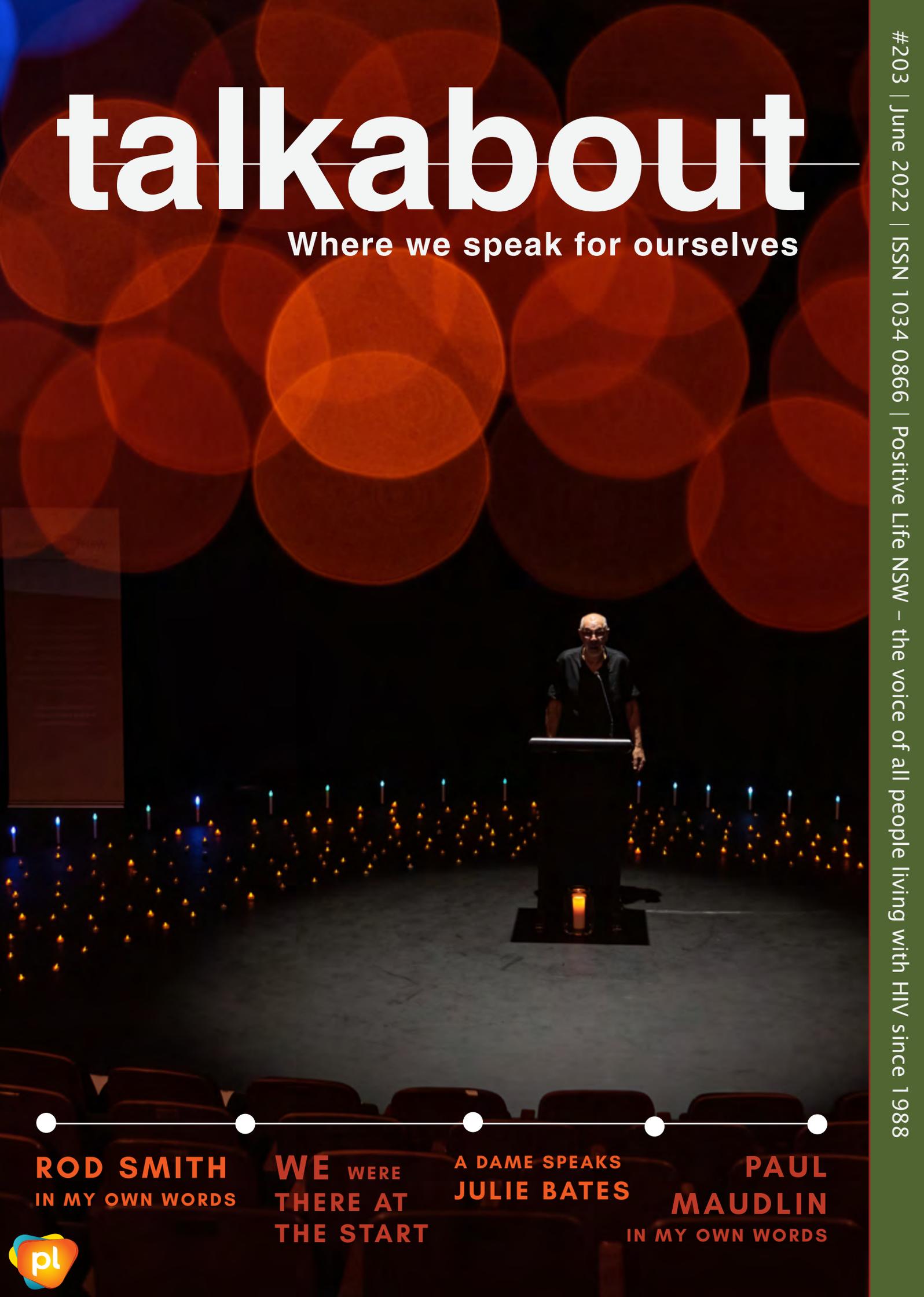


talkabout

Where we speak for ourselves

#203 | June 2022 | ISSN 1034 0866 | Positive Life NSW – the voice of all people living with HIV since 1988



ROD SMITH
IN MY OWN WORDS

WE WERE
THERE AT
THE START

A DAME SPEAKS
JULIE BATES

PAUL MAUDLIN
IN MY OWN WORDS



TALKABOUT

WHERE WE SPEAK FOR OURSELVES

EDITION #203

CONTRIBUTORS

Julie Bates, Jane Costello, Kim, Stephen Lunny,
Louise Houtzager, Marina, Paul Maudlin, Priscilla
Njeri, Rod Smith, Ben White, Lindy Willmott

EDITOR

Craig Andrews |
editor@positivelife.org.au

CONTRIBUTING EDITOR

Louisa Wright |
louisaw@positivelife.org.au

CURRENT BOARD

President Robert Agati | **Vice President** Stephen Lunny
Treasurer Neil Fraser | **Secretary** Sebastian Zagarella
Directors Greg Horn, Natasha Io, Frances Parker
Ex Officio CEO Jane Costello, Staff Representative Craig Andrews

CURRENT STAFF

Chief Executive Officer Jane Costello
Chief Operations Officer James Zagarella
Senior Health Promotion & Peer Navigation Manager Andrew Heslop
Communications Manager &
Positive Speakers Bureau Coordinator Craig Andrews
Aboriginal Health Program Officer Michelle Tobin
Housing Support Officer Melanie Joyce
Peer Support Officer Priscilla Njeri
Peer Support Projects Officer Tobin Saunders
Health Promotions Officer Reuben Matheson
Peer Support Projects Officer Tyler Marks
Administrative and Project Officer Support Ellen Kipper
Consultant Simon Wilson

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ADVERTISING

Simon Wilson |

simonw@positivelife.org.au

SUBSCRIPTIONS & FEEDBACK

www.positivelife.org.au |

editor@positivelife.org.au

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

Cover photo: Rod Smith at the 2022 Sydney Candlelight Memorial

Photographer: Rhiannon Hopley /
RH Photography & Design

This June edition of Talkabout offers reflections from the annual Sydney Candlelight Memorial in May where we honoured our friends and loved ones lost to HIV/AIDS.

In 'A Dame Speaks', Julie Bates shares some poignant memories of the courage and care shown by Professor Basil Donovan and many others from the early years of the HIV/AIDS epidemic in Australia (page 8). After living with HIV for forty years, Rod Smith shares a moving reflection on his lifelong 'companion', and attending his first Candlelight Memorial as a name reader at the 2022 Sydney Candlelight Memorial (page 10). Paul Maudlin shares with us part 3 of his life story (page 16) alongside some of his achievements as a speaker with the Positive Speakers Bureau (PSB). With the benefits of HIV antiretroviral combination therapy, Paul now discovers he's juggling life, love and property challenges along with ever-present health hurdles.

This Talkabout introduces you to a Positive Life staff member (page 13) supporting all men and women living with HIV who identify as heterosexual and her far-reaching impact on the community, alongside our own Stephen Lunny, known and loved by many across the NSW HIV sector, and Positive Life Board Director (page 23). Catch up on some of the consultative work we've carried out at recent forums and surveys over in Talkshop (page 6). The Albion Centre dieticians talk bone health (page 22) while women living with HIV remind us they have been here all along since the early days of the epidemic (page 24) and one far from being an 'emerging group'.

Once again we call on the membership to get in touch if you have any contacts who might be interested in advertising in Talkabout. A couple of small half page or quarter page advertisements would make all the difference to sustain Talkabout. So, if you have any suggestions or questions, please get in touch!

If you have a story in mind, or want to explore how you might be part of Talkabout, please get in touch. **We're on the lookout for the voices of young people living with HIV who can contribute regularly to a column dedicated to younger voices. If you'd like to develop your writing skills as well as contribute to a regular magazine, please get in touch!**

Sharing your story in Talkabout is easy and simple. We can interview by phone, Zoom or face to face as part of 'In My Own Words' to make it quicker than ever to share your story in Talkabout.

Call us on (02) 9206-2177 or 1800 245 677 or by email on contact@positivelife.org.au. I look forward to hearing from you in the near future.

CRAIG ANDREWS
EDITOR

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unusual risks

Life Insurances for people living with HIV, diabetes and other complex health conditions

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An advertisement for 'unusual risks' featuring a man and a woman. The man is on the left, smiling and looking at his phone. The woman is on the right, wearing glasses and looking down. The word 'choice' is written in large, colorful letters at the bottom.

Positive Life NSW represents and advocates on behalf of our members and the NSW Body Positive in a range of NSW HIV/AIDS sector areas. Below are brief details of topics, events and issues we've carried out that impact the interests of people living with HIV in NSW.

HIV STIGMA & DISCRIMINATION

Positive Life NSW is running a survey with community and members living with HIV about the impact and effects of HIV stigma and discrimination on the lives of all people living with HIV. The previous survey on the effects of HIV stigma and discrimination on our lives was in 2018. Four years on, we're updating this work, particularly in light of the COVID-19 pandemic and the latest research conducted by the Centre for Social Research (CSHR) at the University of NSW.

This survey is an opportunity to share your experiences of HIV stigma and discrimination with Positive Life NSW to inform the HIV sector and to assist Positive Life NSW identify and document the ongoing impacts of HIV stigma and discrimination in the lives of all our community members. It will also inform the Positive Life Board from a governance perspective, update and guide staff who engage on a daily basis with community members as well as offer insights into the lived experience of HIV stigma and discrimination.

You'll find a printed copy of this survey with this edition of Talkabout. If you're living with HIV, please complete this survey and return it using the enclosed reply paid envelope.

This survey will be open for three months and closes Friday 5 August 2022.

2022 EMERGING ISSUES FORUM

In February 2022, Positive Life held a community consultation and engagement forum (CCF) to engage with people living with HIV about the impacts of two years of the COVID-19 pandemic on our lives and experiences as we navigated our health needs and the health system.

Attendees travelled from the Sydney inner and outer Metropolitan areas, with 50% of attendees from a culturally and linguistically diverse (CALD) background. Over a third of the group were heterosexual men and women living with HIV, and half of the total group were men who have sex with men living with HIV.

The full day program explored how attendees, all people living with HIV perceived our current quality of life, our future and the strategies or solutions that would improve our quality of life. Emerging themes included isolation, reduced access to healthcare and social support, and challenges to maintaining our quality of life.

Participants were agreed around the importance of security in mitigating the impacts of the COVID pandemic on our lives as people living with HIV in NSW. Security strategies were broken down around an axis of secure housing, finances and health, with issues of dental health, healthy relationships, a reformed migration system, and end of life or pro-choice assisted dying being identified as associated with agency, reassurance and safety.

The 2022 Emerging Themes Community Report has been published on our website and can be downloaded at www.positivelife.org.au/blog/2022-emerging-issues/. The 2022 Emerging Themes Survey Report will be published in the next few weeks and published on our website.

IN THE KNOW

'In The Know', a Treatments and Research evening was held on Wednesday 1 June for all people living with HIV about the latest developments in treatment and research updates. This session focused on the developing and emerging HIV treatments such as injectable ARVs, implants or two drug regimens that are 'in the pipeline' to inform all our community members and build your awareness, understanding and decision making around accessing and using the latest in HIV treatments.

The evening was held at Rydges Sydney Central in Surry Hills starting at 7pm over a buffet dinner. Professor David Lewis, Director of Western Sydney Sexual Health Centre spoke about the development of the long acting HIV injectables and the treatments pipeline. His presentation was followed by Dr Melissa Kelly, Staff Specialist in Infectious Diseases and Sexual Health Medicine at The Albion Centre and the Prince of Wales Hospital who spoke about various benefits and applications of HIV two drug vs three drug regimens.

Professor Lewis' presented an overview on the HIV cellular targets for HIV treatment and prevention, within the lifecycle of the HIV virus from the point of intrusion into a CD4 cell to the production and release of new virions into the body.

He outlined the research into Broadly Neutralising Antibodies (bNAbs) and the points of application to viral suppression, these including HIV prevention, viral suppression and prevention during pregnancy and breastfeeding. He discussed the emerging long acting agents of Cabotegravir

(an integrase inhibitor), Rilpivirine (a non-nucleoside reverse transcriptase inhibitor), Lenacapavir (a capsid inhibitor) and Islatravir (a nucleoside reverse transcriptase translocation inhibitor), highlighting that both Lenacapavir and Islatravir are entirely new classes of HIV treatments.

Professor Lewis discussed the clinical studies (LATTE-2, FLAIR and ATLAS, and ATLAS-2M) around the dual Cabotegravir/Rilpivirine regimens which led into an outline of the Cabenuva injection advantages and disadvantages for people living with HIV. This led into a discussion on who might benefit from this long acting HIV treatment and who would be unsuitable for this option.

Professor Lewis' presentation also included a discussion on the Islatravir clinical trials, and the progress in the Lenacapavir trials and concluded with details about the use of HIV PrEP applications of Cabotegravir (ECLAIR and HPTN 083 studies) and developments in the Dapivirine vaginal ring (RING and ASPIRE Phase 3 trials).

Dr Kelly's presentation offered an overview of the evolution of antiretrovirals and a contextual outline of the various levels of clinical trials and a breakdown of the requirements across different levels and demands of clinical research trials. She outlined the rationale for using a two drug therapy and benefits, using the example

of the TANGO study that was presented at the recent Conference on Retroviruses and Opportunistic Infections (CROI) in February 2022 as an example. Dr Kelly clarified the various questions to consider when deciding between two or three drug therapies and various considerations, needs and priorities that come into that decision.

The evening concluded by 9pm with a number of community based questions that fielded inquiries that included HAND, weight gain, shingles, peripheral neuropathy, conception, pregnancy and menopause.

POSITIVE LIFE STAFFING NEWS

People living with HIV in Mid North Coast to Northern NSW have a new option to reach Positive Life if you want to discuss your support options. Tobin Saunders has joined the Positive Life team based in the Northern Rivers region. He has over thirty years' experience in the HIV community sector in health promotion, peer outreach, community engagement, facilitation, advocacy and research.

Tobin is available to link all people living with HIV, including women and heterosexual people into treatments, housing and employment support as well as support your navigation of the health, disability and aged care systems.

Call Tobin Saunders, Positive Life Peer Support Officer on 1800 245 677 (freecall) or email tobins@positivelife.org.au

Positive Life NSW

Ageing Support



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

Contact Positive Life NSW on (02) 9206 2177 or 1800 245 677 (freecall)

www.positivelife.org.au peernav@positivelife.org.au

It is an honour to be your Mistress of Ceremonies here at the 2022 Sydney Candlelight Memorial.

Each year, our communities come together to respect, honour, and mourn the loss of our loved ones. Positive Life NSW recognises this ceremony as part of the International Candlelight Memorial, held across the world on the third Sunday in May every year with the first memorial held in San Francisco in 1983, as we in Australia had not yet seen the awful impact HIV would have on us. In stark contrast, and luckily for us, we had a government, government advisers, community leaders and allied health professionals that understood the reality without which we would not be where we are today.

In remembering the many lives lost to HIV/AIDS including our friends and colleagues, it is also an opportunity to honour those who dedicated their lives to helping people living with and affected by HIV such as the late Professor Cooper and our keynote speaker today Professor Basil Donovan, welcome Professor, and through events such as this, we continue to mobilise our communities in solidarity and keep alive the memories of our dear ones.

I include a special shout-out to all our health care workers, especially at this time of COVID-19, which brings me to the next item on the agenda, our guest speaker.

Our very special guest speaker today is many things; from a professional perspective, he is the program head of the Sexual Health Program at the Kirby Institute, a NHMRC Practitioner Fellow who recently reluctantly retired from practice saying goodbye to patients he had cared for since their HIV diagnosis. For a lucky few, before the life-saving treatments were available, he was

literally on the frontline of the HIV/AIDS epidemic in Australia, when the first case of AIDS was diagnosed forty years ago..

On a personal level, for many of us, Basil is family and has been there with and for us for all of these years. We have sometimes been naughty children but never a dysfunctional family. We have partied together and mourned together and in between that, got some significant work done. Growing up in the country where his values were established, family is everything to him.

Basil's collaborative work across a range of policy areas and with minority groups is an intrinsic part of our sex worker rights story.

While my peers at the Australian Prostitutes Collective were busy promoting safe sex, so was he and his team but they were also researching and documenting what turned out to be a significant decline in presentations of STIs commensurate with an increase in use of condoms and the role of peer outreach, all of which have been key influencers in policy change.

Sex workers achieved impressively low rates of HIV in our industry while advancing decriminalisation. Without this research and in acknowledgment of our role, we may not have been so well recognised. I believe this recognition supported ongoing Government funding for sex worker organisations.

Basil commenced practicing sexual health medicine at the former *Blue Light Venereal Diseases Clinic* in the Rocks in Sydney in 1979, where I am told the conditions were prehistoric with an open gutter running through the centre of the building to capture the waste!! It was not an area of medicine that most young doctors would even contemplate. It clearly

wasn't a place that women were encouraged to attend!

In the early 80s, he co-founded a specialist sexual health practice in Darlinghurst, so changing the narrative. It was no longer 'VD clinic' or another pejorative descriptive terms for the discipline, but 'sexual health'. Shortly after, alongside his colleagues, he established the Taylor Square Private Clinic which became one of the first HIV specialist practices in Australia at the outset of the HIV/AIDS.

In the mid-80s, he took up the position of Director of the Sydney Sexual Health Centre (SSHC) and was instrumental in increasing the number of dedicated sexual health clinics across NSW and providing opportunities for professional development for a broad cross section of the caring profession. All the while he advanced the cause of sexual health being seen as a respectable profession and area of medicine and allied health services.

Basil wasn't afraid to get out there, meet and treat people where they were at. That was often in the suburbs, in the brothels, in the days when condoms were used as evidence that the place was an illegal brothel and not a health studio as promoted and all that went with that. During this time, the sexual health of sex workers was, as you might imagine, in dire straits without the ability to protect themselves. Unbeknown to us all, HIV was just around the corner.

Being a part of his team on a number of projects. I remember fondly the 1990 contact tracing project to develop the first contact tracing manual for health care providers, to support people living with HIV, TB and other BBVs. While looking for venues for a national seminar, the Professor said "why don't

you try the Quarantine Station?” I thought he was joking...but really how appropriate and indicative of his sense of humor to hold our seminar in such a place that had witnessed all of the early infectious diseases entering Australia.

So it came to pass, a most memorable conference for many. Who can forget or wish to remember the karaoke night!! And the Manual, I think is in its 3rd or 4th edition.

His collaborative work improved relations (and health outcomes) between marginalised communities and their health care providers and set a precedent for others to follow. Under his leadership the SSHC became a world leader in employing peers from marginalised communities, specifically those with sex work experience in health promotion and related roles. This included employing members of the multicultural sex worker community in their research and public health initiatives and activities.

In the mid-2000s, I joined his team again working with his much missed and respected colleague the late Dr. Christine Harcourt and others on the Law and Sex Worker Health (LASH) Projects.

The team by then were known as leading international authorities on the public health and legal aspects of sex work, and had been gathering data on prostitution laws in NSW along with a range of other factors for the previous decade.

The team was now charged with investigating whether the various legislative approaches across Australian jurisdictions provided different health and wellbeing outcomes for sex workers. I was coopted to co-manage the Western Australian component. I'm thinking,

'it's illegal over there, it will not be easy to break into' and he's no doubt thinking, 'who better to send, she's done it all before!!' What faith!

In my rush to get the data and meet with some of the grand old dames of the WA brothel business in their final flourish in the industry, I tripped and fell, and broke my elbow. 'A medical evacuation', said a friend. 'No', he said, 'she can manage'. Maybe he said, 'with one hand tied behind her back', but maybe that was just in my imagination. Anyway I stayed, finished the job with one hand tied behind my back so to speak, and still managed to get to the WA Pride festival that was on at the time.

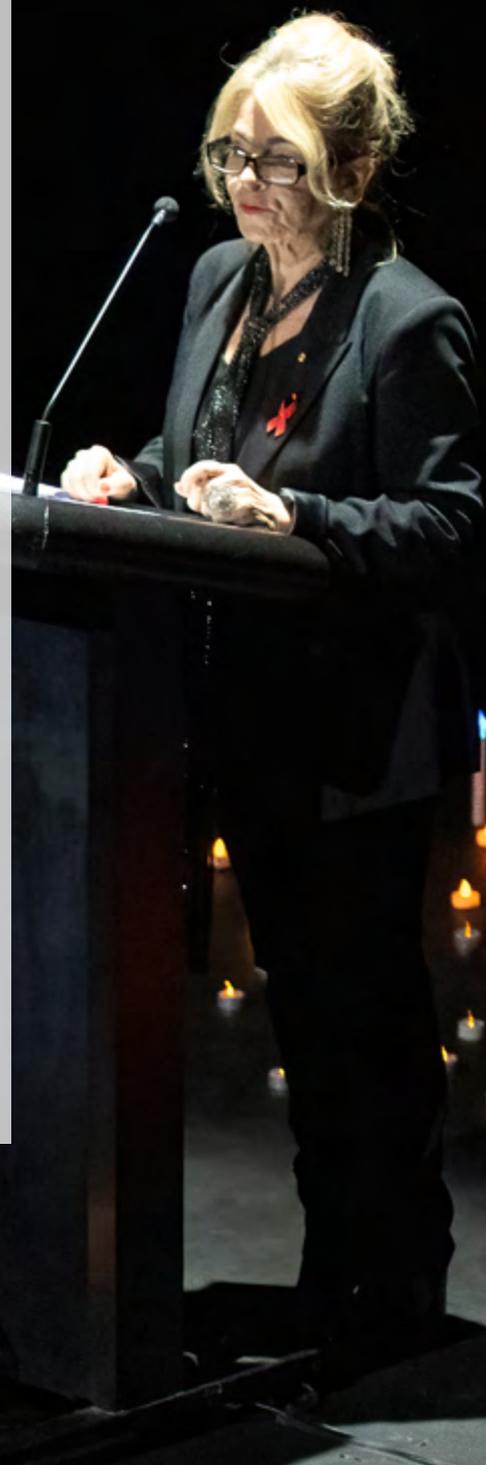
Wrapping up now, for those who know him, Basil wears his heart on his sleeve and is an ally like no other. All evident in his interview in the 2007 documentary *Rapant: How a City Stopped a Plague*, when we were holding on to our emotions, Basil let it rip. When asked 'what was the most difficult thing he had to face', the resounding answer, "the relentless deaths of young people before effective anti-HIV treatment became available," and he considered his greatest life achievement at that time to be "contributing to the control of HIV in Sydney and elsewhere – and surviving (just)." Well I am very glad you did survive Professor! As for how you chose your career path, I will leave that for you to share.

Your friendship, your service and contribution to public health and social justice and the caring of people living with HIV and those at the end of their life is exemplary matched only by your humanity.

I am proud to call you a friend.

Welcome Professor Donovan.

– Julie Bates



Rod Smith was one of sixteen name-readers at the 2022 Sydney Candlelight Memorial. While he has lived with HIV for forty years, this was the first Candlelight Memorial he has ever attended.

“I’m sure I contracted HIV after a session in 1982,” Rod said. “I can’t prove it, other than knowing what was happening at that time. It was one of my first experiences with S & M. I was curious. My fuck-buddy had just come back from San Francisco, and it was a 24 hour experience with lots of drugs involved.

“So that’s how I knew when I contracted HIV because I remember seroconverting, thinking, *‘oh, this is different.’* But I didn’t put two and two together. After that, I just went off sex and moved out of the city.” Three years later, Rod was diagnosed with HIV and told he had perhaps three to six months to live. He had just finished his nursing training in 1985.

For the first six months, he remembers thinking over and over again, *‘Oh my God, I’m dying. I’m dying. I’m dying.’* 40 years later, I’m still here,” he says.

“After that period, I was basically celibate, there was no sex for 30 odd years. I just didn’t want to transmit HIV to anyone else.”

“Reflecting back, had I known that I would still be here now, I would have bought houses and done all that. But your life gets put on hold, and you’re waiting to die.”

Over the next 10 years, Rod’s entire group of friends passed away. “It became a very isolated world. As I was losing friends, I wasn’t making new friends. So when the last of my friends passed, it became a very lonely world. I moved away from the city and got involved in drugs. That was my escape.

“There were times where I just didn’t want to be here anymore. Especially in the first decade when I lost so many friends and you go through survivor guilt. They’ve all gone; why am I still here? That’s when life started becoming quite bleak.

“When friends were dying and unwell, I was so busy looking after them, cooking dinners, saying goodbye to people and going to funerals.. Then all of a sudden, all that stopped. It was like, *Okay, I’m at this sort of crossroads. I don’t know which way to go.* Then as time progressed, it was like, *‘hang on, I don’t feel any different. And that’s when the fight began. You know, ‘I’m going to beat this.’*

“When I reached the 10-year mark, I became suddenly this new category of ‘long term survivor’. Then when I reached 20 years, my whole way of thinking around HIV was, *‘Hang on, this is not my enemy. This is my companion.’* And I think that’s the difference where I’m at peace with it. Now HIV is my constant companion.

The medication journey

“The first HIV meds that became available was AZT. Prior to that my CD4 count was really high. I did a lot of drugs! I’m quite surprised that I survived all that.

”I went on AZT for two weeks. My specialist said, *‘Look, I would recommend it, because it’s the only thing that’s around.’* I can understand coming from a medical model point of view. But at the time, it was like ‘no, my body’s telling me not to take it, and I’m gonna listen to my body.’ So I just said to my specialists, *‘you know what, I don’t like this. My body says, don’t.’* But yeah, I just knew after two weeks. I felt better without it. Best decision I ever made.

“So I was not on medication for about four or five years. Then Don Packham, my specialist, said, *‘look, there’s American study called the Crest study, would you like to be part of it?’* Sure! I’ll be a guinea pig. Within two weeks, I had an undetectable viral load. Prior to that it was beyond measuring.

“When we started getting to more therapies, antiretrovirals and protease inhibitors, I was taking 28 tablets a day. Some had to be taken with food, you had to set your alarm four times a day. It was a real pain in the ass. It was complex and tiring. But I did it, and I stuck with it.



“I just look at how far we’ve come now. It’s one tablet a day for some people. I’m on four meds now, two twice a day, the other two once a day. In terms of my health, apart from the odd little issue, and for my age, I think I’m doing okay.

“Then we had the combination therapies, which made things a lot more simple. Currently, my viral load is undetectable. My CD4 count is over 1200, which is bloody brilliant.

”I had a few issues over the years like peripheral neuropathy, osteoporosis, facial lipoatrophy (that was from a drug called *stavudine*). That stopped me wanting to re-engage with my gay community. I just looked in the mirror and just saw this skeletal face and everyone was saying, ‘Oh, he looks sick.’

“I was living with my two best friends who were gay. I had some straight friends but this social world was all drug related. I wanted to move away from that lifestyle. Then it was a conscious decision: I needed to get back to my community.

“As luck would have it, I went along to a *Seven to Nine* meeting with Hedimo. Thank you very much Positive Life! That was a major shift in my life. It took me a few attempts to actually walk through the doors. I’d go into town and then, ‘nah!’ I go back home again and feel really frustrated.

“When I finally did go through with it, I was met with such warmth from the group! That was me reconnecting with the gay community, and of course, that’s where I met Andrew. We’re in a sero-discordant relationship and we’ve been together 11 years now.

“I started volunteering with the Needle and Syringe Program (NSP). Andrew was the team leader. After he moved to NUAA, Nic Parkhill from ACON said ‘*we want to appoint you to the role of Coordinator*’, so I’ve been the coordinator now for six years.

Attending the 2022 Candlelight Memorial

“Attending my first Candlelight was very powerful. I had never been. It wasn’t that I wasn’t interested in going, but it just brought back too many memories of the early days and the loss and the grief. Back then, you reached a point where you can’t cry anymore. You are just all teared out. It was very desolate.

“For some reason, I think it was the fact that February was my 40th anniversary. And I thought *this is the time*. When I was asked to read names, I thought ‘Okay. Yep.’

“That photo [on the Talkabout Cover] is beautiful. I used it on my Facebook as a very poignant moment. *Soundcheck. Empty seats*. It actually represented the loss. It was really symbolic. It was a very powerful day. Thank you for letting me be a part of it.

“The names that I read out, there was no one I knew! But when other people reading, I was ‘ah, God I remember partying with you.’ But they weren’t sad memories. They

were actually joyous memories of our days partying. So while there was a sense of solemnness to the event, in here my heart was actually singing.

“The first 20 years, we had good times, but there were bad times as well. Drugs became my therapy. At the time, I thought well, I’m gonna bloody well die. If I get a bad result, I’ll give it up. I didn’t.

“Even in the depths I was never suicidal, but I was a risk taker. I would push boundaries. Now, I think, ‘*God how the hell did I get away with it?*’ Now I lead a pretty sedate sort of life. The work that I do is relevant to my situation.

“I think working at the NSP, it’s almost like destiny, one of those things meant to be. Meeting Andrew, who became my boss, then we became partners. We have a very loving, supportive relationship. So, my life is blessed. I’ve always taken the time just to smell the roses.

“I think it’s also about surrounding yourself with the right people. In the past 20 years, I’ve been surrounded by good people. It’s nice reaching my age, I can look back and think, ‘well, it’s been an interesting life!’ Where I’m at now is a really good place.

“Now at 40 years [living with HIV] is a whole new chapter for me. Still, I think day by day. I live for the moment, yesterday is gone. Tomorrow will be a new day, I can’t plan five years down the track.

“Yes, I made some bad choices in the years gone by, but it got me through. It allowed me to survive. And people can say, but you were taking drugs? Well, absolutely. Which is now why I work in Alcohol and Other Drugs. It’s like, been there, done that.

I’m quite open about my past track history at the NSP. I’m not talking out of a textbook. I’m talking from lived experience. *Oh, you’re one of us!* I’m so proud of our needle and syringe program. It’s different, it’s more holistic, and we look at the whole person. We remove stigma, we remove judgment, and we’re working with some of the most marginalised, vulnerable people in our community. They come into our service, and they leave knowing they’ve been seen and heard. Andrew’s my great mentor, he’s brilliant in the industry. The staff that I have are all amazing people.

“I’m quite open about my HIV status. Why not? I’m not ashamed of it, I don’t see it as a something to be ashamed of. Back from those early horrific days, someone asked me, ‘*So, what was it really like?*’ And I said, there’s only two words that describe it. Absolutely terrifying.

“So now, I’m just ‘*right place, right time*’. Life is good.”

Postscript: Rod Smith works out of the Needle and Syringe program (NSP) in the foyer of 414 Elizabeth Street. He has endless time and compassion for people who inject drugs. People can pick up a full range of injecting equipment as well as condoms and lube, free and single use, including accessing 24-hour disposal bins and finding out where there are sharps disposal locations.



Priscilla is a Peer Support Officer at Positive Life NSW responsible for developing the programs for all people living with HIV who identify as heterosexual.

She brings over 10 years counselling and clinical community work in the Kenyan HIV sector at Kenya Network of Women with HIV/AIDS (KENWAS) offering person-centred support to community members living with HIV. Priscilla is responsible to ensure women living with HIV, both newly diagnosed and living longer term with HIV, have timely access to peer-based support that empowers them to make informed decisions about their health. She has a firm commitment to the health and wellbeing of all people living with HIV from culturally and linguistically

diverse (CALD) backgrounds and is a strong voice for the well-being and human rights of all people living with HIV in NSW, especially women.

During her time at Positive Life, Priscilla has developed two online groups for women living with HIV. The first one, *The Women's Room*, welcomes all women living with HIV under 45 years of age. This group explores many of the issues relevant to women who may be considering conception and pregnancy and other fertility issues. The second group, *For Women*, welcomes all women living with HIV over 45 years of age and explores many issues relevant to women in this age group such as menopause, diabetes and heart health.

A third group, *The Men's Room*, is about to start at Positive Life, for men living with HIV who identify as heterosexual. This will be facilitated by a man living with HIV focused on the specific needs and health issues of men.

"I am aware of men who identify as heterosexual and living with HIV for over 20 years, who have never found any support or contact in their HIV journey at all," said Priscilla. "They end up being very isolated and facing a number of life challenges. Without support or just someone to talk to who understands their lived experiences, they are find themselves increasingly vulnerable in all areas of life which impacts their health and wellbeing."

Priscilla also has key responsibility for the Social Club that welcomes people living with HIV who identify as heterosexual. She has a specific focus on raising awareness within the NSW positive heterosexual community about their options to live well and healthily, including access, health equity and human rights. As she says, "every month at the Positive Life Social Club, I speak with heterosexually identifying people living with HIV from CALD backgrounds who carry enormous amounts of stigma and fear, even here in NSW.

"Recently, a woman told me directly that she cannot participate either face-to-face or online, because of the HIV stigma in her community here in Australia. This is only one issue women face living with HIV. There are some very simple levers of access and inclusion that fail for many members of our community from CALD backgrounds.

With over 180 people who identify as heterosexual registered with Positive Life NSW, and growing weekly, Priscilla is a key point of contact in the agency. She is supported in this role by other colleagues on staff.

"Here at Positive Life, I am very passionate about my role and I'm looking forward to the day when heterosexual people and in particular women living with HIV will be fully involved in their community.

"I believe it is only when the heterosexual community living with HIV become engaged and fully included in the broader NSW Body Positive community, that their emerging needs will be recognised to a much greater extent than we see today.

By the same token, others living with HIV also need to realise that heterosexual people living with HIV do exist in this state. This will only start to happen when this group become authentically immersed in the community and start making their own self-determination around their quality of life and lived experiences.

Since 2020, Positive Life NSW has offered an expanded program of support and social inclusion groups to heterosexual men and women living with HIV, gay and bisexual men living with HIV, and specific supports targeting the needs of women living with HIV.

For more details call Positive Life NSW on (02) 9206 2177, 1800 245 677 (freecall) or email contact@positivelife.org.au

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



Positive Conversations - a monthly online event for all people living with HIV

- Call Positive Life NSW (02) 9206 2177, 1800 245 677 - or email contact@positivelife.org.au

Have questions about HIV treatments?
Need to talk about your HIV and health?

Contact Positive Life
02 9206 2177 or 1800 245 677 (freecall)

Positive Life NSW



Treatments Support for all people living with HIV

- Call Positive Life NSW (02) 9206 2177, 1800 245 677 - or email contact@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



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.

Before you read more about my story covering 1999–2004 below, I want to first share some achievements that added more diversity to the PLWHA (NSW) (now Positive Life NSW) Positive Speakers Bureau (PSB) during its infancy spanning the years 1997–2004.

November 1997 - March 1998: 'Versa' phone chat line and peer support forum

'Versa' was an innovative and ambitious pilot project administered by the PSB in collaboration with Roche Products, which supplied an unconditional educational grant. 'Versa' was specifically for people living with HIV to be able to speak with a peer (or join a chat line) and to ask questions on any HIV related issues and get treatment advice. TeleTech International supplied the physical facility and technology at their St Leonards headquarters. Six PSB speakers were trained to facilitate the service and were rostered on Thursday to Sunday nights.

May 2000: PSB Rural Video

This video was produced and sold to schools and other organisations as an extension of the 'The Human face of HIV/AIDS' concept used by the PSB to reach at-risk groups in the communities outside metropolitan Sydney. The video was launched at the HIV/HCV and Sexual Health Forum in Ballina on 18 November 2000. Levi Strauss Australia and the AIDS Trust of Australia provided the funding which, with the aid of Training, Health and Education Media Pty Ltd, presented three PSB speakers in the video doing what they normally did in 'real life' situations in high schools throughout NSW.

July 2002: 14th International AIDS Conference, Barcelona Spain

I represented PLWHA (NSW) and the PSB as well as the Sydney AIDS Memorial Quilt Project at the conference, for three tasks. The first was doing a presentation using the rural video and talking about the PSB Project and its successes. The second was roaming

the conference precincts after my presentation donating 200 videos that had been transported to Spain several weeks beforehand as training aids for other international HIV/AIDS organisations. The third was attending the International AIDS Memorial Quilt display, reading the names of Australians whose memorial panels were featured on the section of the quilt that I took with me as hand luggage, on behalf of the Sydney AIDS Memorial Quilt Project.

There were many educational conference firsts and highlights for me. However one of the best was seeing Nelson Mandela and Bill Clinton speaking on stage during the closing plenary. They were not only passionate about HIV/AIDS issues, but also extremely interesting and very funny, complimenting each other.

The only sour thing occurred on the day I departed Spain, when I was pick-pocketed after using an ATM and found myself with no money or credit cards. The police refused to help me and, because of that, I had to resort to jumping train barriers at two railway stations to get to the airport on time. My flight home had an extended delay in Malaysia and the airline provided a free buffet meal with alcoholic drinks in the terminal. I went through twice. The following year the PSB was funded by the Sydney Quilt Project to send PSB speakers to schools in rural areas, taking sections of the quilt with them. Speakers would incorporate information about the people that were represented on the quilt panels, together with a brief history of the Sydney Quilt Project while also telling their own story. These talks were very popular and a novel way of educating students about the implications of HIV.

October 2003: 'Enjoying Sex Safely' starring Con Le Dom

This easy-to-understand printed resource was designed and focus-tested with teachers and high school students doing their Personal Development, Health and Physical Education (PDHPE), Crossroads and Sciences curriculums before it was launched in 2003. This pocket booklet successfully addressed questions posed by students during PSB speaking engagements.

In part, the 2003 promotional flyer said:

"Written in an easy-to-understand style, with a bright and creative design, 'Enjoying Sex Safely' includes an overview of life with HIV/AIDS such as personal perspectives from, and information about the impact of treatments on, the lives of people living with HIV/AIDS. The engaging Con Le Dom graphic then guides the students through the practice of safe sex, including the importance of using condoms, hints designed to put the students more at ease with shopping for, carrying, storing, and using condoms to protect them from sexually transmitted infections (STIs)."

The PSB recommended that the distribution of the booklet should be at the Principal's or teacher's discretion. This was done successfully and copies made available to all students taking part in a PSB talk.

1999-2000: The rocky road ahead, or perpetuity

On 5 January 1999, my birthday coincided with first of four radiotherapy sessions to treat the remnants of Kaposi's Sarcoma (KS) after chemotherapy fifteen weeks previously. The first two sessions resulted in unsightly bruising on my lower legs with both knees also



becoming severely swollen. Dr Cassy Workman thought that the blood flow in my legs was being restricted, with blood pooling in my upper legs. New lesions started to appear all over my body. I was sent on sick leave with orders to stay off my legs. There was very little change for the third session. However, the fourth session resulted with a marked improvement in my left leg, yet my right leg was worse. The radiation oncologist, Dr Chris Milross thought my problem was lymphatic and suggested it was likely Dr Goldstein would instigate another round of chemotherapy. Two weeks later, after being reviewed by Dr Goldstein, fortnightly chemotherapy treatment with Doxorubicin (Dox-SL) recommenced because alternative drugs were considered too toxic.

A month after re-starting chemotherapy, the swelling, size, and colour of most lesions on both legs had significantly improved, which made walking easier. Unfortunately, once again I needed the intervention of the drug Thalidomide, due to severe oral mucosal irritation and

swelling of my tongue which made eating solid foods and drinking hot liquids very difficult. Fortunately, Thalidomide was fast acting, and this situation was resolved a couple of weeks later.

Concern continued about my abnormal Liver Function Tests (LFTs), and I was referred to another Prince of Wales Hospital specialist, Dr George Marinos, who suspected my high LFTs were lipodystrophy and/or antiretroviral drug related and he wanted to perform a liver biopsy to try and rule out anything more serious. The biopsy was scheduled for 28 August 1999. A month prior I had received confirmation that I had been granted partial funding from the Polish Foundation of Humanitarian Aid to attend the 9th International Conference for PLWHA in Warsaw in mid-August. The biopsy went ahead as planned and revealed that my liver was dying and there was also fibrosis. The antiretroviral drug Nevirapine that I was on was withdrawn the same day, due to a severe reaction. This was the first

change in my mega HAART (Highly Active Antiretroviral Therapy) regimen since November 1997.

Unfortunately, I was not allowed to travel and had to withdraw my scholarship to the conference. My manager, Ryan McLaughlin, took my place. Shellee Williams (nee Korn) brought me back a book, "Auschwitz voices from the ground" from her visit to Auschwitz. We had planned to visit Auschwitz together and so the book was a very thoughtful gesture.

By early September 1999, I was exhausted and mentally drained but otherwise well, despite losing a lot of weight. Things seemed so bad that I thought I was going to die. While in that headspace I decided there were four things that I needed to achieve. These were to visit my first ex-wife Janice and her partner Rhonda in California; separate from Rodd, my partner of a year; sell my house in St. Peters to move to the NSW Central Coast; and lastly, to retire from the workforce and my voluntary commitments.



Holden Street Sexual Health Clinic, Gosford 2004 / Unknown photographer

I wanted to apply for a life insurance buy-back scheme which was being advertised at the time, and Dr Cassy Workman provided me with a letter to support my application. The last paragraph in this letter states:

“It is difficult to give a precise opinion regarding Mr Maudlin’s prognosis given that the cause of his liver disease has not yet been defined. However, both the rapid loss of CD4s and Paul’s development of rapid and extensive Kaposi’s Sarcoma (an AIDS-defining condition) do not bode well for a long-term outlook.”

The scheme turned out to be an insurance scam and the letter was never submitted. My life insurance policy remained intact. Friends tried to warn me that if I sold my house I would never be able to re-buy in the Sydney Metropolitan area again. Eighteen months later this advice would come back to haunt me and was one hundred percent correct. Tongue in cheek, I put the house on the market before going on holidays to the USA.

At the time, people living with HIV were prohibited from entering the USA and taking HIV antiretrovirals with them. Given I was still on a large cocktail of drugs, to get around the entry problem I decided to camouflage ten days’ supply of medication by putting it all together in a large glass bottle which was wrapped in aluminium foil to hopefully avoid detection if x-rayed, before wrapping in bubble wrap and enclosing in cardboard box and mailing to Janice several weeks beforehand. To secure my entry into the USA I neglected to declare my HIV status on my entry documentation.

I successfully entered San Francisco without any problem, and Janice picked me up and off we went. My parcel reached its destination without incident, and I had a lovely holiday with the girls and their family who I had not seen since 1974. The only problem I had while I was in the USA was returning to San Jose from Sacramento after attending Janice’s

parents golden wedding anniversary. We were travelling in the girls’ camper van which broke down in a remote area of California, and we were almost attacked by a rogue mountain bear.

After getting home, Rodd and I agreed to separate. My house sold in late October, and I purchased a brand-new house in Blue Haven. In mid-November I was feeling more in control of my life when suddenly I was shocked to find myself needing to begin a third round of chemotherapy. The move to the Central Coast took place in mid-December 1999 as planned and Rodd helped me with some of the moving, getting me settled in the new house, and visited a couple of times before we lost contact altogether several months later. Unfortunately, I did not have quite enough money to buy the house outright and needed a small mortgage while still needing to continue working. Due to the circumstances described below, I ended up working ten more years before I was able to finally semi retire in June 2010. I had to continue to commute by train to Sydney for work and medical appointments. My theory was that regardless of whether I lived longer or died, buying another house, was cheaper than renting and if everything went south, it would be an asset for my adult children.

The new year (2000) commenced with more ongoing problems with swelling and bruising in both legs and so I was allowed to work remotely from home for a brief period. Twenty-two years ago, working remotely from home was a very innovative concept and something not many employers were embracing. For PLWHA (NSW) it meant phoning the office to say that I would be logging into my office computer, a paper sign would be placed on the screen that would alert staff that they could not use that machine while I was logged on from home. I used this time to do administration work for the PSB and continue writing the project’s first training and workshop manual. I

returned to work after a month and began planning and recruiting for the fifth Positive Speakers training course.

In February 2000, the chemotherapy and radiotherapy treatment for KS were finally over, twenty months after starting. Apart from minor skin shrinkage on my lower legs, it took a further two years for my legs to totally heal, with KS disappearing completely and hair growing back. I often kept my head hair short (a throwback from my Navy days) and was very pleased that I had not lost it or any other bodily hair. I have not had any more recurrences of KS since, but did have another unrelated HIV issue with my left leg in 2019. Sorry, you will have to wait until the last instalment (Dec ’22) of my story to find out what it was.

2000-2001: A new man and the tale of three houses

Commuting was extremely draining, and so my solution to that was to stay in a share household in Alexandria during the week, returning home only on weekends. This arrangement worked well until I answered a personal advertisement in the *Sydney Star Observer* and eventually met Adam who gave me a new lease on life and sense of purpose. We have now been together 22 years.

For a couple of months, I was living between three homes, and so something had to give. I moved out of the share accommodation, and stayed with Adam while he was house-sitting his ex-partner’s house while he was working overseas. I sold the house in Blue Haven, putting the house contents into storage on the Central Coast (I must have known something) and returned to Sydney a year after first re-locating. This accommodation was short lived. The house we were staying in was being sold, so we decided to buy our own house. After weeks of searching, we decided to buy a more affordable house in Blue Haven in March 2001, mainly because my workdays had been reduced therefore making the train commuting much more bearable.

2001-2002: SESAHS HARP Unit and PLC Surry Hills

I took a year-long hiatus from the PSB to accept a temporary Health Promotion position with the HIV and Related Programs (HARP) Unit at South East Sydney Area Health Service (SESAHS). Three months later the Area appointed me to administer the Positive Living Centre (PLC) while a tender process was under way, after the Centre's Management Committee was dissolved following the defunding of the service by the Minister of Health.

My brief was to manage and continue the day to day activity service and deal with financial and legal aspects of the defunding on behalf of SESAHS, while also keeping all aspects of the service running while minimising the disruption to clients and dealing with their fears and concerns.

During this time, I secured office space for the Luncheon Club AIDS Support Group after successfully negotiating lease arrangements with SESAHS and oversaw the smooth operation for their Monday meal service, which catered for 120 PLWHA.

Clients were devastated when they were advised that one of their friends, who had been missing for several weeks, had been murdered by his partner who was also another client of the service. The attack on the Twin Towers in New York also occurred shortly after that and understandably this was a very traumatic time for everyone.

I have fond memories of staff, volunteers and clients at the PLC

and was happy to be able to give some hope and certainty during very difficult times during the six months that it took for the tender to be awarded to ACON.

2002-2004: Lipodystrophy, Fusion Inhibitor, and diagnostic scans

Other than the complicated process of participating in six studies over eighteen months, life settled down somewhat. Despite being compliant taking HIV antiretrovirals, my blood results continued to be disappointing, necessitating several changes in medication either due to resistance or drug reactions. Two of the studies were to investigate the long-term effects of Rosiglitazone (Rosey) for controlling lipodystrophy to determine whether it would increase fat in my arms, legs and cheeks and decrease fat in my waist. The lipodystrophy studies had the added requirement for regular ultrasounds, dual energy x-ray absorption (DEXA) and computerised tomography (CT) scans. Four years later I found myself enrolled in one of the early studies for Poly lactic Acid (Sculptra) injections for facial lipoatrophy and four years after that I needed a series of follow-up injections once Sculptra was licenced.

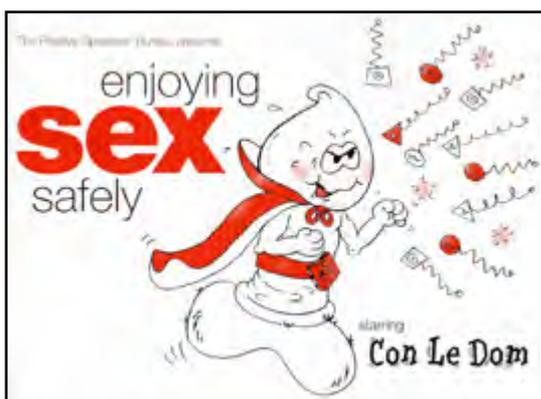
Two more studies designed to explore whether the amount of HIV in my blood could be controlled by using the subcutaneous injectable infusion inhibitor Enfuvirtide, together with other antiretrovirals while excluding all nucleoside reverse transcriptase inhibitor (NRTI) drugs followed. I hated doing the twice daily injections, and when going on holidays in New Zealand, I found

it very awkward having to mix the drug up beforehand. These two trials did not improve my CD4/VL and so I was extremely happy when they ended. The other two studies were to compare the safety and effectiveness of the boosted protease inhibitor (PI) Tipranavir with a low dose of the PI Ritonavir to control my viral load.

Two months after starting work at the Holden Street Sexual Health Clinic in Gosford, Dr Jeffrey Post performed a fifth and final liver biopsy, which once again did not reveal why my LFTs were abnormal, along with evidence of having mild steatosis, minimal lobular inflammation and no fibrosis or portal inflammation. The consensus was that the nineteen changes in drug regimens since beginning antiretroviral therapy in 1995 had contributed to my suspected liver disease. In October I reluctantly transferred my HIV care to Dr Michael Boyle at John Hunter Hospital Immunology Department in Newcastle, when my CD4 count was 70 with a viral load of 100,000 copies. Two weeks later after yet another HIV antiretroviral change, my CD4/VL counts were 180/60,000. By year's end, there was a considerable difference (225/59,500). My improved results would be short lived.

In the next edition I will write about the period 2005-2010, severe drug reactions, another AIDS-defining condition, phenomenal immune restoration, osteopenia, semi-retirement and PSN/HUGS, Better Health Self-Management Program, and another Positive Speakers Group.

Paul R Maudlin OAM, JP



Front Cover and Back Cover of *Enjoying Sex Safely, 2003* / Geoffrey Williams & Assoc / Twisted Hair Productions



Get in Touch!

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

Emails should be short (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.

Email Talkabout
editor@positivelife.org.au or

Write to Talkabout
PO Box 831
Darlinghurst NSW 1300

JUNE

- 16 **[+Connect]** Sydney 7pm
For all people living with HIV, our partners, friends and family
- 22 **Peer2Peer** Sydney 6pm
For all gay and bisexual men living with HIV

JULY

- 2 **Heterosexual Workshop** Sydney 9am
For all people living with HIV who identify as heterosexual
- 5 **Positive Conversations** Online 6pm
For all people living with HIV
- 8 **Social Club** Sydney 6pm
For all people living with HIV who identify as heterosexual
- 12 **For Women** Online 6.30pm
For all women living with HIV over 45 years of age
- 20 **Digital Mentors** Sydney 12.15pm
For all people living with HIV
- 21 **Peer2Peer** Newcastle 12.30pm
For all men living with HIV

AUGUST

- 5 **Social Club** Sydney 6pm
For all people living with HIV who identify as heterosexual
- 8 **The Women's Room** Online 6.30pm
For all women living with HIV under 45 years of age
- 14 **[+Connect]** Liverpool 12noon
For all people living with HIV, our partners, friends and family
- 16 **Positive Conversations** Online 6pm
For all people living with HIV
- 17 **Digital Mentors** Sydney 12.15pm
For all people living with HIV
- 20 **Forum** Sydney 9.30am
For all people living with HIV
- 24 **Peer2Peer** Sydney 6pm
For all gay and bisexual men living with HIV

FOR MORE DETAILS

Call (02) 9206 2177 or 1800 245 677 or email contact@positivelife.org.au

Event details are correct at time of printing.



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

Bones are living structures that are essential for movement and keeping you upright. They also act as a bank for minerals like calcium.

It's especially important for people living with HIV to be conscious of their bone health. People living with HIV are more at risk of having osteoporosis (weak and brittle bones) and osteopenia (inability to replace old bone quickly). A healthy diet and the right kind of exercise ensures that your bones remain strong and healthy so you can live a long and active life.

What do I need to do to keep my bones strong and healthy?

1. Include Calcium in your diet

Calcium is important for building and maintaining bone strength and structure. Calcium rich food sources in your diet will maximise your bone health and reduce risk of fractures. To be sure you have enough, aim to have at least 2 to 3 serves of reduced fat milk, yoghurt, cheese or alternatives daily. One serve is either 1 slice of reduced fat cheese, a small tub of reduced fat yoghurt, 1 cup of milk or 1 cup of milk alternative with added calcium eg almond, oat or soy milk. Note: reduced fat dairy products are higher in calcium than full cream.

The most common sources of calcium include dairy products. If you don't include dairy in your diet there are other options. Fish with bones, tofu (produced with calcium), and calcium enriched dairy free milks are all good sources of calcium. Canned sardines, tuna and pink or red salmon with bones are great to include. Make sure you check the label of dairy free alternatives and tofu for added calcium. There are also other options such as calcium-fortified orange juice and cereals.

Talk to a Dietitian about how you can meet your body's calcium needs from food. Also ask if there are any interactions between calcium and the HIV medicines you're taking.

2. Get your Vitamin D from the sun

Vitamin D is also an important nutrient that is crucial to your bone health. Studies have shown that vitamin D deficiency is common amongst people living with HIV. Vitamin D helps you absorb the calcium that you get through your food. If you don't get enough vitamin D every day, your calcium levels will also be affected. The main source of vitamin D is through regular daily sunshine. During summer, a few minutes of mid-morning or mid-afternoon sun exposure to your arms and hands, almost daily, is recommended. Spend more time in the sun during cooler seasons and always remember to wear sun protection.

3. Stay active

Weight bearing exercise is the best kind of exercise to strengthen your bones. Examples of weight bearing exercise are:

- Walking
- Weight training
- Climbing stairs
- Hiking
- Tennis

Simply walking for short trips instead of driving or taking the stairs instead of the elevator will help strengthen your bones.

– The Albion Centre Nutrition Team



**When day comes,
we step out of the shade of flame
and unafraid.
The new dawn balloons
as we free it.
For there is always light,
if only we're brave enough to see it.
If only we're brave enough to be it.**

– Amanda Gorman, 2021

PLNSW DIRECTOR /STEPHEN LUNNY

I am a 54 year old queer man/community worker/ people person/ lover of life. I guess I've lived with HIV around 20 years, seroconverting in a time when effective drug treatment was in place. As a result I became more focussed on living the long life I was going to be able to have, than acknowledging the years I had lived with HIV. I do what I can to improve my wellbeing while striving to live days when I forget I'm HIV positive, was and is my mantra.

I've been a Positive Life NSW Board Director for five years now, since 2017. I was attracted to being a Positive Life Board Director because I believe I have something of value to offer in this role. I chose Positive Life NSW because I have personally experienced something of the value of peer-based organisations before and knew it was the best fit for me.

A person living with HIV can make a tremendous impact on a Board like the Positive Life Board. Everyone with HIV has a lived story that informs them and can inform an organisation like Positive Life. By being a Board Director, you help give voice to the Body Positive narrative in NSW. Voices can also be silent but impactful. The act of standing strong and visible with your fellow Board Directors on an issue, in troubled times, or simply as a body of people, can also have a quiet but powerful impact.

I'm an optimistic person who has a community lens on most things. By that, I mean principles like equity, social justice and inclusion are of great importance to me. This is part of the strength I bring to the Board.

My life with HIV has encouraged me to focus on my wellbeing. I have always had that in my gaze since seroconverting. On reflection I do think it has made me live more in the present, the now. Finally it has given me another community to connect with.

As we live longer, I believe one of the main future priorities for the NSW HIV community is around a focus on ageing with HIV. It's vitally important that we work hard to address the barriers to connection with our community/ties for all people living with HIV.

As a queer urban Sydney man, I feel well connected and am grateful for the many services/ organisations that are available to me. This is not the experience of all people who live with HIV. It's vitally important that we work extra hard to address this particular issue, so no one living with HIV gets left behind.



WOMEN'S SPACE

The Candlelight Memorial is an annual event held to remember and honour those who have passed away from HIV/AIDS and to reflect on the challenges that people with HIV/AIDS faced during the height of the AIDS pandemic.

The Candlelight Memorial is of special significance for women living with HIV. Firstly, because women were there too. Sometimes we hear the phrase 'women living with HIV are an emerging community'. The reality is, women were diagnosed with HIV right from the beginning of the HIV/AIDS epidemic, we lived through the times of the AIDS pandemic and we overcame many adversities. And secondly, because women who have been more recently diagnosed can identify with many parts of the stories of women who have been living long-term with HIV.

Through conversations with women who are long-term survivors, it is clear that we had many unique struggles. With an uncertain life expectancy, it was difficult to plan for the future. Some women living with HIV never experienced motherhood. Pregnant women diagnosed with HIV were often discouraged from keeping their babies. There was also a lack of support and no real sense of belonging.

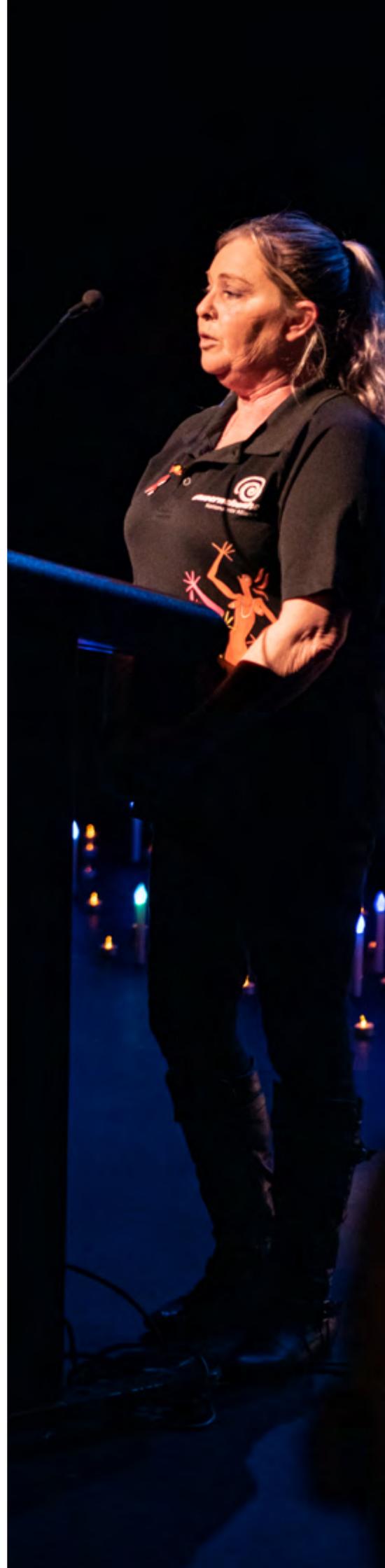
At support groups, many of us were often the only woman in the room, and it was common to be told we had come to the wrong place. There was very little in the way of resources, research and information for women living with HIV. Many times, the void was filled by inaccurate information, HIV discrimination and stigma. There was also the multitude of tablets that had only been tested on male bodies, that had to be taken at specific times and dosages, resulting in various short-term and long-term side effects and health problems.

With medical advancements, life has improved for everyone living with HIV/AIDS. It is no longer seen as a death sentence, and women living with HIV today have a much better quality of life in all aspects such as career, relationships and family. These advancements cannot erase the past, which has had a permanent effect on our lives as women who are long-term survivors.

The Candlelight Memorial is also relevant for women who have lived long term with HIV and also those who have been more recently diagnosed. Despite having different journeys, many people can personally identify with some of the challenges of women who are long-term survivors. Today, women are still being diagnosed late. The majority of us who live with HIV, without knowing it for many years, become increasingly ill without knowing the cause or having any treatment. Unfortunately, the myths, inaccuracies and stigma about HIV/AIDS are still prevalent, and these have untold impacts on our lives as women living with HIV.

The Candlelight Memorial is so very significant for women living with HIV/AIDS. We have been there since the beginning – and we're still here.

For more details on any of the events or groups in the Women's Space, get in touch with Positive Life NSW by phone (02) 9206 2177, 1800 245 677 (freecall) or email contact@positivelife.org.au to speak to another woman living with HIV.



LIVING WITH HIV?

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Voluntary assisted dying will soon be legal in all states. Here's what's just happened in NSW and what it means for you.

Voluntary assisted dying will soon be legal in all states. Here's what's just happened in NSW and what it means for you.

The last state in Australia, New South Wales, [has today passed its voluntary assisted dying bill](#). This means the vast majority of the population now lives in a jurisdiction where voluntary assisted dying is, or will be, lawful.

However, voluntary assisted dying is not yet available in NSW. As in other states, there is an 18 month implementation period to establish how it would work.

Here's what's just happened in NSW, what can be learned from other states, and what to expect next.

What does the NSW legislation say?

The NSW legislation reflects the broad Australian model of regulating voluntary assisted dying in the other states.

It will be available to an adult with decision-making capacity who has an advanced and progressive illness that will cause death, likely within six months (or 12 months for neurodegenerative conditions).

Other eligibility criteria include the patient is suffering, and their choice is voluntary and enduring. Two senior doctors, who have completed mandatory training, will each conduct a rigorous eligibility assessment. A voluntary assisted dying board will be established to ensure the system is operating safely.

Each state has variations in its voluntary assisted dying laws. One of note in NSW is a person can choose between taking the medication themselves or having a health practitioner administer the medication to them.

In other states, although both methods are allowed, self-administration is the default method.

What does this mean for people in NSW?

During the 18 months between the legislation passing and implementation, NSW can benefit from the experience of the [five other states](#).

Victoria was the first to have legalised voluntary assisted dying [in 2019](#) followed by [Western Australia in 2021](#). Tasmania, South Australia and Queensland have also passed similar legislation but their laws are not yet in force.

This just leaves the Australian Capital Territory and Northern Territory without voluntary assisted dying laws.

One key lesson for NSW is for people to access voluntary assisted dying, there needs to be sufficient doctors trained and willing to participate from the start.

This requires the legislatively-mandated training to be ready early, and incentives and supports provided for doctors to undertake it. It also requires knowing which doctors may be open to participating.

A linked issue from Victoria and WA is the critical facilitating role played by "[voluntary assisted dying care navigators](#)". These health professionals support patients, families and other health professionals who wish to seek or provide voluntary assisted dying, and guide them through the complex eligibility assessment procedure.

This role includes the vital function of connecting patients with doctors. The establishment of this small but critical workforce, well before voluntary assisted dying is available, is essential.

A final observation from other states' implementation is the importance of education for key stakeholders.

Potentially eligible people can only access voluntary assisted dying if they are aware it exists. So there needs to be a clear public communication strategy to tell the community that voluntary assisted dying is available, and where to find more information.

Building awareness for the broader health workforce (beyond those providing voluntary assisted dying) is also important.

These two groups are linked. Evidence shows people wanting more information about end-of-life law are likely to ask health professionals.

What happens in NSW once the law kicks in?

The end of 2023, when the NSW voluntary assisted dying laws are expected to begin, may seem a long time away. But the experience of other states has been that there is little time to waste. This is a major health, legal and community initiative and implementing it is challenging.

There will be patients seeking access to it as soon as the law begins. So the system must be ready.

In WA, there was higher-than-anticipated early demand. Within the first four months of the law being implemented, [50 terminally-ill people chose to die](#) using voluntary assisted dying. As a state with a significantly larger population, NSW should be anticipating more.

So work must start now to ensure that as soon as the NSW law begins, there is a functional system ready to support people eligible for voluntary assisted dying.

How about the territories?

As territories, the NT and ACT cannot legislate on voluntary assisted dying. The Commonwealth passed legislation in 1997 to prohibit this.

However, there have been repeated calls for this to change. If this were to occur, this would open the possibility for the territories to follow the lead of the states and pass their own laws permitting voluntary assisted dying.



[Ben White](#), Professor of End-of-Life Law and Regulation, Australian Centre for Health Law Research, [Queensland University of Technology](#) and [Lindy Willmott](#), Professor of Law, Australian Centre for Health Law Research, Queensland University of Technology, [Queensland University of Technology](#).

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