

talkabout

Where we speak for ourselves

#204 | August 2022 | ISSN 1 034 0866 | Positive Life NSW – the voice of all people living with HIV since 1 988

MEDICATION
MYTHS &
MISCONCEPTIONS

DO I HAVE TO
DISCLOSE
AT WORK?

MOVING
TOWARDS
DIGNITY

PAUL
MAUDLIN
IN MY OWN WORDS

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TALKABOUT

WHERE WE SPEAK FOR OURSELVES

EDITION #204

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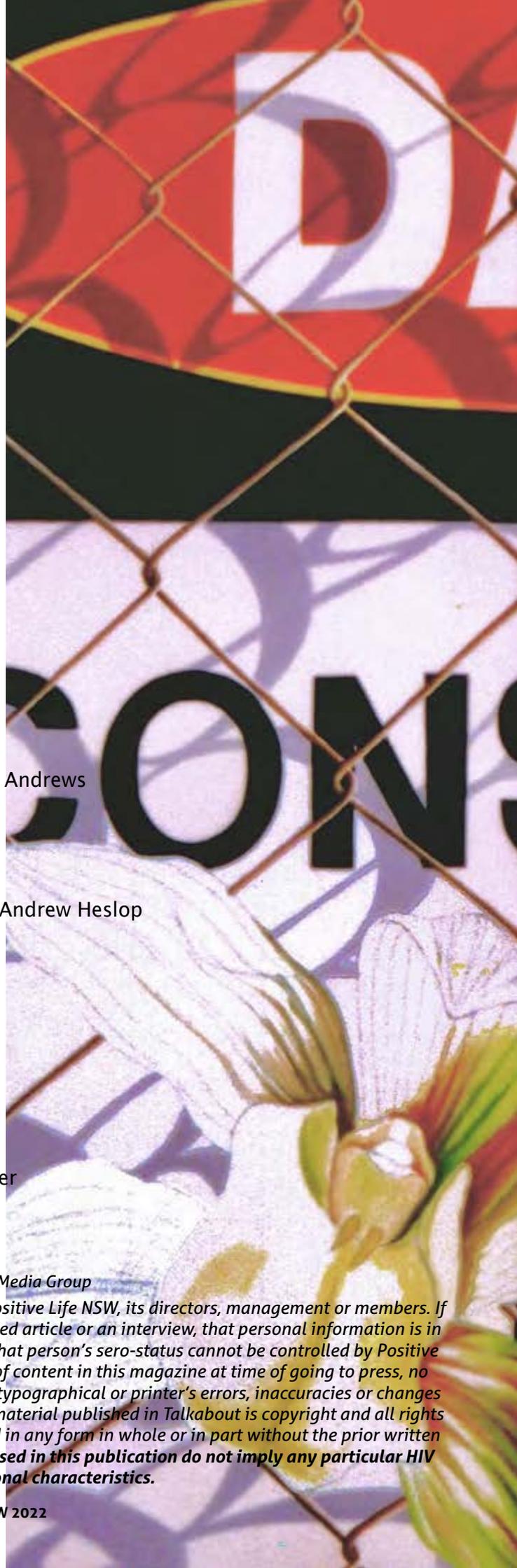
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Acknowledgement and thanks
to our eagle-eyed proof readers
for this edition

Cover photo: Peter Schlosser, Church Street Newtown
Inside artwork: Peter Schlosser, 2001 - Danger Construction

This August edition of Talkabout offers reflections about life with HIV, medications, coming to terms and the perennial question - Do I have to disclose at work?

Community member and PSB Speaker, Peter Schlosser, has shared two photographs to showcase in this Talkabout. The cover image is a photograph of a 2015 building mural by [Fintan Magee](#), in collaboration with [Elliott 'Numskull' Routledge](#), both large scale contemporary public Australian artists. Peter's 2001 'Danger Construction' appears on the inside front cover (page 3) to complement the urban cover theme.

This edition highlights personal experiences and concerns across employment (page 8), persistent myths and misconceptions about HIV medications (page 10), and an endearing reflection on moving beyond internalised HIV stigma (page 22). In his own words, Paul Maudlin shares a fourth instalment about living with HIV from 2005 to 2010 (page 17).

We report on some of the consultative work we've carried out with heterosexual people living with HIV over in Talkshop (page 6) and introduce you to another Positive Life staff member (page 15), who many of you may already have met in his previous role as a Health Promotion Officer with ACON Northern Rivers. The Albion Centre Nutrition Team talks dental health (page 26), while we raise the delicate topic of anal cancer for women living with HIV due to the very common Human Papillomavirus.

Once again we call on the membership to let us know 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 contact us. **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) 8357-8386 or 1800 245 677 or by email on contact@positivelife.org.au. I look forward to hearing from you in the near future.

CRAIG ANDREWS
EDITOR

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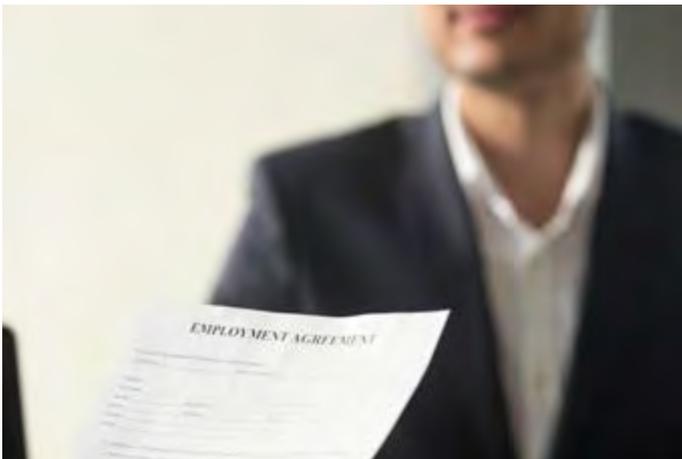
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Positive Life NSW represents and advocates on behalf of our members and the NSW Body Positive in a range of NSW HIV/AIDS sector areas. Below are brief details of topics, events and issues we've undertaken that impact the interests of people living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

IN THE KNOW

Advanced Notice: 'In The Know', a Treatments and Research evening will be held on Thursday 13 October 2022 for all people living with HIV about the latest developments in treatment and research updates on quality of life, ageing and HIV-associated neurocognitive disorder (HAND). This evening session held in Sydney city, will inform our community members living with HIV about research on quality of life, offer the latest information on ageing and living with HIV, as well as raising your awareness and building your understanding about HAND.

REDUCING ANAL CANCER

The online March 2022 Conference on Retroviruses and Opportunistic Infections (CROI) reported on the outcomes of the Anal Cancer HSIL Outcomes Research (ANCHOR) study. This ground-breaking clinical trial was halted early because of the high success rates.

Anal cancer is caused by Human Papillomavirus (HPV), which can cause changes to the skin around and inside the anus. These changes are called "high-grade squamous intraepithelial lesions" or HSIL. Most HSIL will go away on their own, and not all anal HSIL will develop into cancer.

However, some will become cancer over time and can eventually spread to other parts of the body. While the ANCHOR study has demonstrated that the rate of progression from anal HSIL to cancer is higher than expected, it has also proven that removing HSIL in people living with HIV, significantly reduces their chances of progressing to anal cancer. Without treatment, the risk of anal cancer for women living with HIV is about eight times higher than women without HIV, and for men who have sex with men (MS) it is 39 times higher than MSM without HIV.

While discussing anal screening is uncomfortable for both the person living with HIV and the healthcare provider, this discussion is one of the best preventative strategies to take care of your long-term health. Using a procedure called high resolution anoscopy, a specialist can examine the anal canal and perianus using a magnifying device, and check for abnormal cells. Should HSIL be detected, the specialist will be able to discuss and evaluate with you, your options for treatment.

HETEROSEXUAL PEOPLE LIVING WITH HIV

Positive Life held the annual 'Life Beyond' workshop for all people who identify as heterosexual who are living with HIV on Saturday 2 July in Sydney city. Despite an extremely wet, windy and cold day, the turnout for this increasingly popular event enjoyed another opportunity to meet peers living with HIV and reduce their personal sense of isolation.

Based on the input from the Heterosexual Workshop Advisory Group, this time the workshop programming focused more on the personal stories of people living with HIV, while services and agency information were included in an updated resource contained in the workshop 'show bags' provided to each attendee.

We were joined by Dr Catriona Ooi, Director Sexual Health, Northern Sydney Area Health Service; Surry Hills Neighbourhood Centre Community Programs Coordinator Stephen Lunny; Clinical Psychologist Patrick McGrath from The Albion Centre; and Associate Professor Lucette Cysique, Senior Researcher and Neuropsychologist, St. Vincent's Hospital. Topics included the latest on HIV research, options to maintain a healthy eating plan on a budget, mental health and wellbeing while living with HIV, and the latest on cognitive health, ageing and HIV. Positive Life Senior Health Promotion Manager Andrew Heslop provided a practical outline about travelling with HIV medication, along with general tips to keep in mind, and important considerations when travelling given that COVID-19 is still a varying risk factor in different environments. The day concluded with a community conversation about what matters for people living with HIV who identify as heterosexual.



**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) 8357 8386 or 1800 245 677 (freecall)

DO I HAVE TO DISCLOSE AT WORK?

Starting in a new workplace is daunting enough without worrying about whether you need to disclose your HIV status to your new employer. Some of us are comfortable disclosing our status and have no issue telling people.

However, for others, especially newly diagnosed people living with HIV, knowing how to disclose or even whether you need to at all can be overwhelming.

Generally, in NSW, you are **not legally bound** to disclose your HIV status to any employer or potential employer.

There are very few situations where you can be legally asked about your status and may be required to have a HIV test. These include joining the Australian Defence Force (ADF), employment in aviation (commercial, domestic, international) and working as a Health Care Worker (HCW).

HCWs must follow standard universal precautions procedures which means they treat all patients or clients universally, as if everyone was already living with HIV, hepatitis B (HBV) or hepatitis C (HCV), and other blood-borne viruses (BBVs). HCWs can work without any restrictions unless performing EPPs (Exposure Prone Procedures). EPPs are procedures performed in a confined body cavity where there is poor visibility, which may pose a risk of cutting yourself with a sharp tool, tooth, or bone.

If you decide to disclose in the workplace, it's recommended that you carefully consider all your options first. While your current supervisor or manager may be understanding, once your status is on file or known in the workplace, you can't get that information back.

Your next supervisor may have a different attitude which may cause complications later. Even so, employers have a duty to maintain employee confidentiality and are bound by the *Federal Privacy Act 1988*.

If you are applying for a new role, or filling out induction forms, depending on the job or the workplace, you may come across a question relating to prescription medications.

While HIV antiretrovirals (ARVs) are prescription medications, you do not need to list these on the forms. This question is asked in regards to any medications that are either mood-altering (antidepressants such as Valium) or impact your cardiac health, such as blood pressure medications, cholesterol, or other heart medications.

The reason your employer may be asking this varies depending on the type of job you are applying for. You're likely to find this question if you are going to be operating heavy machinery, working in a health care setting, or driving long distances. Others want to know this as a duty of care; should something happen

to you, they would then be able to provide crucial information to emergency responders.

Some people living with HIV take a sick leave day when they go for their general three- or six-monthly HIV check-up. Most employers will require you to provide a medical certificate when you take sick leave.

In this case, it's a good idea to ask your doctor to leave off any HIV-identifying terms or language and instead state something around 'general check-up and pathology'. This is entirely true and should not be seen as misrepresenting your doctor's visit. It is also about protecting your privacy and your doctor should understand this.

Some industries enforce random drug tests which are strategies to see if you have been using illicit substances (such as meth, pot, MDMA) that could endanger yourself or colleagues in the workplace.

HIV ARV medications, particularly efavirenz, sometimes cause a false positive result for THC (tetrahydrocannabinol) found in cannabis, and the prescription medication benzodiazepine (benzos) will prompt the medical examiner to inform your employer.

If this happens, a letter from your HIV doctor indicating that you are on prescription medication that may cause a false positive drug test is advisable. By law, you cannot be tested for HIV without your specific consent.

If you are dismissed or prevented from undertaking certain duties that are relevant to your role because of your HIV status, this may amount to unlawful discrimination and legal advice should be sought within 21 days of dismissal.

So, unless you are performing surgery, flying jumbo jets, or defending our freedoms, you do not need to legally disclose your HIV status to any employer unless you personally feel it is safe to do so and that your privacy will be kept intact.

If you have any questions about living with HIV, navigating your employment options including your study, training, paid (casual, part-time or full-time) or voluntary work options or decisions about disclosure, you can get in touch with Positive Life NSW on (02) 8357 8386, 1800 245 677 (freecall) or drop us an email on contact@positivelife.org.au

If you feel you have been discriminated against because of your HIV status, or your privacy has been breached, you can contact Positive Life for a referral to lawyers who can offer you legal support and advice about your situation.

– Tyler Marks

REEMENT

MYTHS & MISCONCEPTIONS

There is a lot of information out there today about HIV, including many myths and misconceptions. For this article I have focused on misconceptions around medication.

Why do I need to take medication if I feel healthy?

After a person is diagnosed with HIV, it can take many years before they actually start to feel like there is something wrong or they feel sick.

While they may feel healthy, without HIV medication HIV is progressively damaging their immune system by reducing the number of their CD4 cells. CD4 cells are a vital part of the immune system which fights off infection. These are a type of white blood cell that are the body's natural defence system against pathogens including bacteria, viruses and fungi.

Starting HIV antiretroviral treatment (ART) early, ideally at the time of diagnosis, has been shown to help preserve the immune system and prevent the development and onset of advanced HIV disease or AIDS.

ART reduces the amount of virus present. This means that a person living with HIV who is on effective HIV ART and is virally suppressed (less than 200 copies of HIV RNA per milliliter of blood) cannot sexually transmit HIV. This is known as U=U (Undetectable equals Untransmittable) or TasP ([Treatment as Prevention](#)).

Advanced HIV disease or AIDS is a clinical diagnosis. It occurs when HIV has weakened the immune system so much, that it can't fight off infections that it normally would be able to do. These infections are called opportunistic infections and they usually occur when the CD4 cell count is below 200 copies/mL. Your usual CD4 range is between 500 to 1500 copies/mL. A weakened immune system also means people are more likely to develop certain cancers.

In Australia, very few people who are on effective HIV ART develop AIDS. This is because their prescribed ART slows the progression of HIV. A person living with HIV on effective ART is likely to die with HIV rather than from HIV.

Starting ART early also reduces the chance of developing heart disease, HIV-associated kidney disease, HIV-associated neurocognitive disorders (or memory issues), bone diseases and some cancers. ART allows most people living with HIV to live full and healthy lives.

So while you may feel OK without medication, you are much better off starting your HIV ART as soon as possible.

Am I going to experience side effects if I go on medication?

All medication can cause side effects, and these can vary from person to person. With current HIV ART, these are generally mild and do not persist for more than a few days or a few weeks.

Nausea, fatigue, feeling light-headed and trouble sleeping are common short-term side effects. If you do experience these or any other side effects, talk to your pharmacist. They may be able to provide advice on how to reduce or manage these side effects. If you find you cannot tolerate your current medication, talk to your doctor as there are many medication options available today for people living with HIV.

In discussion with your doctor, there may be another HIV antiretroviral combination that suits your medical needs and also your lifestyle.

Does it matter if I miss a dose of my HIV medication?

One of the most important things once you commence HIV ART is adherence – i.e. taking the prescribed medication as directed. Ideally, you don't miss any doses. However, if you miss a dose or two occasionally, don't stress or beat yourself up. We are all human and from time to time this can happen for a variety of reasons.

Current HIV medication is potent and highly effective and an occasional missed dose (say once a month) should not impact the medication's ability to control your HIV.

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However, if you start missing doses on a more regular basis, say every week, you can put yourself at risk of your HIV not being suppressed.

When your HIV is not suppressed, this can affect your immune system and can result in an increase in viral load and a fall in CD4 cell counts. It may also result in the development of resistance, and the failure of one or more drugs in your treatment regimen. This may mean that your next regimen is more complex and may consist of more than a single tablet a day.

Importantly, if you are not virally suppressed, it is possible for you to transmit HIV to your HIV-negative sexual partners if other precautions are not being implemented (such as your partner on PrEP, using condoms etc).

Taking your medications at the same time each day can help you remember to take them. However you do not have to take them at exactly the same time each day.

My advice is to tie them in with a daily activity. It may be taking them at breakfast or with your cup of coffee in the morning. If you get up at 7am during the week but on the weekends at midday, that is OK.

The best time for you could be when you brush your teeth, when you get home from work, or when you go to bed. The exact time may vary day to day, but linking it in with a specific daily activity can help you to remember to take your medication.

What do I do if I miss a dose?

If you are on a single tablet once a day regimen, and you normally take your medication in the morning (say 8am) and you forget, you have until about 12 midnight (or a 16 hour window) to take the missed dose. It's safe to resume with your usual next dose in the morning at 8am.

If you take the same medication twice a day, I would recommend a four to six hour window to take the missed dose.

For anything outside of these times, I would recommend skipping the dose and resuming at your next usual dosing time.

Do not take a double dose. Taking a double dose is unlikely to be of any benefit, and you also risk experiencing adverse effects.

Setting alarms/reminders on your phone or using various apps (e.g. [NPS MedicineWise](#)) can also help. A dosette box or blister-packaging your medication may be of benefit. Taking medication can become so routine you may not specifically remember whether you have actually taken it. I personally use a dosette box, and if I am unsure whether I took my medication, I can visually check to see if that is the case.

If you find you struggle with adherence, please have a chat to your friendly pharmacist who may offer further handy hints to help.

Can I use herbs, vitamins and supplements instead of medication to treat HIV?

The answer is NO.

There are no herbs or supplements that have been shown to be effective in treating HIV.

Many people in the community take vitamins and supplements for a variety of reasons, and it is important to check with your pharmacist if there are any interactions with your HIV ART.

Can I have a break from HIV medication?

The simple answer is NO.

This is not recommended by any current treatment guidelines.

In the early days of HIV treatment, when many of the drugs had debilitating side effects, some clinicians advised people living with HIV to have a 'structured treatment interruption'. However, we now know that these 'treatment holidays' can result in worse outcomes for people living with HIV.

Today, structured interruption of HIV treatment is not recommended outside of controlled clinical trials. Commencing and staying on ART is a long-term and life-time commitment until a cure is found.

Having a break from ART can result in an increase in viral load (and with that transmission risk), a lowering of CD4 cell counts increasing the risk of HIV disease progression, and they also can potentially increase the risk of resistance developing.

However, there is one caveat, see below.

If I find that I am going to run out of medications before I can get a new refill, what should I do?

If you just have run out of repeats on your prescriptions but can access your regular pharmacy, they may be able to provide you with an 'emergency supply' to cover until you can obtain a new prescription.

A second option if available is to access treatment through a [NSW Sexual Health Clinic](#) or via a Hospital Emergency Department.

If you have no access to a doctor or a pharmacy, this is my recommendation. Keep taking your medication daily as prescribed until they run out. Stop. Have a clean break and then recommence once access to your HIV ART is available.

Do not try to spread your medication out by taking it every second or third day. You are much more likely to develop resistance to your HIV ART if you do this.

Seek advice from your doctor or your pharmacist on any unintended ART breaks.

If you do have any concerns, or questions about HIV, the medications you are taking, please talk to your pharmacist or your doctor.

– Bruce Hamish Bowden
Clinical Pharmacist (HIV)



Understanding the aged care system and the different services available for older people, can be difficult and complex. There are often many different options depending on individual needs and circumstances.

Seniors Rights Service is a community organisation dedicated to protecting and advancing the rights of older people. They offer free and confidential telephone advice, aged care advocacy and support, legal advice and community information to seniors across New South Wales.

Their aged care advocates support older people who receive Commonwealth-funded aged care services at home or in residential care, as well as their carers or family members, to understand and uphold their rights.

Seniors Rights Service has **two Aged Care System Navigators** who can offer older people information, support and assistance to understand the aged care system and what options are available to them. Navigators provide information, support and assistance to understand, choose and access appropriate age care services.

Seniors Rights Service delivers the Aged Care System Navigator program in two regional NSW regions - Lisa and Rob support older people in and around these regions.

Lisa Johnston is based in Dubbo and works across the Orana Far West region. Lisa can be contacted on 0468 449 086.

Rob Ingram is based in Batemans Bay and covers the South Coast region. Rob can be contacted on 0482 168 088.

The regional Aged Care Navigators will know what types of services are available locally, depending on the level of care or support an older person might need. There are home care services to assist seniors to stay at home and residential aged care services if an older person can no longer remain at home and needs full time care.

If an older person is being cared for at home, short term respite care may also be available.

To contact a Seniors Rights Service Aged Care System Navigator please call the navigators on the phone numbers above if you live in their area.

If you need support to navigate the Aged Care System **in other parts of NSW**, visit the [Council of the Aged website for contact details](#) or call Seniors Rights Service on 02 9281 3600 or email info@SeniorsRightsService.org.au



**Seniors Rights
Service**

AGED CARE SYSTEM NAVIGATORS

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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) 8357 8386, 1800 245 677 –
or email contact@positivelife.org.au



Treatments Support for all people living with HIV
– Call Positive Life NSW (02) 8357 8386, 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 on telephone (02) 8357 8386, 1800 245 677 (freecall) or email contact@positivelife.org.au

Tobin is a Positive Life Peer Support Projects Officer based in the NSW Northern Rivers region. He brings more than twelve years' experiences in HIV health promotion in northern NSW and is responsible for outreach and support to all people living with HIV in this region.

"I'm a peer, meaning I've lived with HIV long-term myself," Tobin says. "My role is about supporting people particularly in this region of the Northern Rivers, so they know we're here and can talk to us when they need some support or information."

When asked what towns are included in the region, Tobin says: "The Northern Rivers region begins south of Grafton, which is situated on the Clarence River, then heads north along the coast, including the towns of Yamba, Iluka (the mouth of the Clarence River), Evans Head, Woodburn, Coraki and Ballina (which sits at the mouth of the Richmond River).

"Heading further north is Lennox Head, Byron Bay, Brunswick Heads, Ocean Shores, Pottsville, Kingscliff and arriving at Tweed Heads on the Tweed River, the boundary of NSW and Queensland. Heading west, adjacent to the border with Queensland, the Northern Rivers region arcs gently south-west to include many small towns and villages such as Tyalgum, Kyogle and Casino. Arcing north and closer to the coast, the southern tip of the region comprises a group of mountainous national parks.

"Lismore, arguably the cultural centre of the Northern Rivers and with a sizeable LGBTIQ community, sits roughly halfway between Ballina and Casino. From Ballina to Lismore, if you zigzag in a north-east direction, you'll pass through Nimbin, Mullumbimby, Uki and Murwillumbah. You'll traverse Alstonville, Wollongbar and Goonellabah heading back to the border with Queensland at Tweed Heads, Coolangatta, a porous boundary of cross border services with people working, socialising and accessing services here."

As a local, familiar with these towns he clarifies: "Of course, there are individual needs and challenges to each of these places. I'd say the overall challenges are transport, housing affordability, jobs and all those things that big cities plan and implement. Currently most of the Northern Rivers is profoundly impacted by the recent flood catastrophes. The physical and emotional rebuild is ongoing and a logistical nightmare."

Around the time Tobin started with Positive Life, the Northern Rivers community experienced a catastrophic flood that broke records. Tobin went on to explain, "in fact, a really big weather event cleared out a lot of the waterways detritus about five years ago. The recent disastrous weather event is of historical importance. This was severe flooding followed by endless rain, a mini-cyclone,



followed by a second catastrophic flood event, worse than the record breaking first one. So it was just exhausting. Some people in this area are now finding the sound of rain, triggering and traumatising, which is tragic, really. Such a lovely sound."

As a Peer Navigation Officer, Tobin reflects on his initial move into the Northern Rivers back in the mid-90s. "What I was planning to do was to die. You know, nip on up here and find a little hut in the jungle and quietly fade away, talking to the birds. As we know, combination antiretroviral medication (cART) has essentially revolutionised HIV treatment and people's health, so it wasn't long before I hit a more soul-searching, adjustment period. I found I couldn't just nip down into the corner shop, have a coffee with friends, access a good variety of food and culture, visit a local sex-on-premises venue, or use any number of services in an affordable way."

He goes on to say, "There's a slower pace and I think for a lot of people, they revisit what's important. So in a way, coming here is a silence that can be deafening, both physically and also emotionally, and that took a couple of years to adjust to."

"Being here as a Positive Life Peer Navigator, means I'm around to have yarn or a phone call with, and also to share ideas with other peers."

People living with HIV in the Northern Rivers area can contact Tobin by phone or email.

"We can have a tea, coffee, water or a walk. It could be about brainstorming what options you have while you're here, looking for services or finding new friends, whether you're planning a move back to the big smoke, or adjusting to the quiet," he said.

Call Tobin on 0493 438 346 (Thursdays), or (02) 8357 8386 or email contact@positivelife.org.au

INTRODUCING



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.



(L-R) Michael Williamson, Paul Maudlin & Neil Summers, Holden Street Sexual Health Clinic / Photographer: Unknown

2005: 'Maureen the Switch Bitch' aka 'The Pox Doctor's Clerk'

By the time January 2005 rolled around, I had been at the Holden Street Sexual Health Clinic (HSC) in Gosford for a year and had well and truly settled into my substantive position as the clinic's sole Administration Officer. HSC wasn't the first health care setting that I had been employed at, however it was the first time I had held a non-commercial/military logistics and inventory control position in health care.

My first health workplace setting was in 1982–1985 when I was the Petty Officer in charge of the Hospital Medical Store at HMAS Penguin in Balmoral, Sydney. The second was in 1996–1997 when I was employed as the Inventory Control Officer (Operating Suites) at the Mater Misericordiae Hospital in North Sydney.

I thoroughly enjoyed working at all these health settings, however HSC provided the most dynamic and rewarding experience where I interacted and supported a small multi-disciplinary team of clinicians while also supporting not only clients with general sexual health issues, but also people living with HIV/AIDS.

My primary role amongst many other administration functions was staffing the front-of-house reception and I often referred to myself as 'Maureen the Switch Bitch'. I was trained to triage clients to learn whether they were

part of our priority population groups and then make appointments as required. The official address for HSC is 69-71 Holden Street Gosford, however it was standard practise to drop the '71'. Without a doubt, new clients found it very amusing when told the clinic was located at 69 Holden Street, the irony was not lost on them.

Not long after starting there I found myself needing to seek more specific HIV health information for my own needs from staff who I had come to appreciate and admire and who accepted me as part of the small team. I was still travelling to Newcastle for my HIV monitoring, usually on my acquired days off (ADOs). The Clinic Director; Dr Debbie Allen and the Career Medical Officer (CMO) in HIV/Sexual Health, Dr Kym Collins were always keen to hear about my ongoing topsy-turvy HIV antiretroviral struggle, drug resistance and adverse reactions.

In 2005, I continued studying online with Sydney University for my Graduate Diploma of Health Science (Sexual Health), which I had started in late 2003 when it was a face-face course known as the Diploma of Sexual Health Counselling and administered through the Australasian College of Sexual Health Physicians and Sydney Sexual Health Centre at Sydney Hospital. I also began studies with NSW Health for the Certificate 3 in Business in April 2005, so study wise I was kept very busy in my spare time.

IN MY OWN WORDS / PAUL MAUDLIN

2005: Training another Positive Speaker Service

The local Central Coast HIV care and support service, Positive Support Network (PSN) wrote to me in June 2000 when I was co-ordinating the Positive Speakers Bureau (PSB) expressing an interest in having a training proposal put together for myself to visit Gosford to conduct training, so that it could have its own local people doing positive speaking engagements.

A proposal was put together and sadly at the time did not go ahead due to the lack of funding by the PSN. Knowing my previous background in positive speaking co-ordination, in early 2005 I was asked by the then Central Coast Area Health Service (CCAHS) HIV and Related Programs (HARP) Manager, Karen Nairn whether I would consider conducting training for members of the PSN.

Ironically the area health service had found funds to support the training for the PSN. So, after planning and recruiting for suitable trainees, I agreed to do two weekend workshops which resulted in the PSN having its own Positive Speaker Service (PSS) with six new positive speakers. Little did I know at the time that I would take over as the manager of the PSN five years later, and that PSS would go on to prosper in a similar way to that of its city cousin, the Positive Life PSB.

2005: Chronic Disease Self-Management

In July 2005 I was selected to undertake training for the CCAHS Chronic Disease Self-Management Program (CDSMP) which was based on the Stanford University

model in the USA. I became one of the project's workshop leaders and so began a ten-year association with that Program doing seven workshops (one a year) at local Neighbourhood Centres which would each run over six weekends.

During this time, I also initiated, planned and facilitated three specialised CDSMP workshops for HIV/Sexual Health, PSN and women living with Hepatitis C/HIV. It was extremely rewarding seeing people not coping very well, sharing their lived experiences and gaining new skills in a non-threatening and supported environment often empowering them to better cope with their chronic illness.

I successfully gained both my Grad Dip of Health Science degree and Certificate 3 in Business in March and April 2006 respectively. I thought I was done with studying however, eight years later I found myself studying Training, Assessment and Evaluation (TAE) in preparation for applying for Community Services part time casual teaching position for the Hunter Institute of TAFE (now TAFE NSW).

2006: Dangerous Hypersensitivity and another Opportunistic Infection

Twenty-six months at HSC had come and gone very quickly and my employee/patient status at the clinic suddenly changed. I needed an urgent in-house consultation with the Dr Kym Collins, due to experiencing ongoing unexplained worsening chronic diarrhoea and weight loss over the previous four

(L-R) Paul Maudlin & Michael Williamson, Bus Advertisement Gosford Guy's Clinic / Photographer: Unknown



months. Stool cultures which Kym ordered failed to show any growth, ova cysts or parasites, microsporidia, cryptosporidium nor giardia antigens. Kym referred me to a local gastroenterologist Dr John Dowsett, who after reviewing me in early May scheduled an endoscopy/ colonoscopy four weeks later at Gosford Hospital. I have a family history of anal and colon cancer (my father, but he did not die from either) and coupled with my earlier history of opportunistic infection with Kaposi's Sarcoma (KS) in 1998, John was concerned that I might have had internal KS or Mycobacterium Avium Complex (MAC) or other significant infection/neoplasm.

Two weeks (13 May 2006) before the procedures were to take place, I fronted at work as usual. This time, I was covered from head to toe with tiny red blotches which had developed overnight. Dr Collins was away that morning and so when Dr Debbie Allen saw my condition, she told me to immediately cease taking Abacavir as I had experienced a hypersensitivity reaction and to urgently contact Dr Mark Boyle (my HIV prescriber in Newcastle) without delay. I contacted Dr Boyle and he agreed with Debbie's prompt advice and wanted me to also cease taking Kivexa. Two days later Abacavir and Kivexa were replaced by Truvada, which may have contributed to other problems a year later. This was the last of eight changes in my HIV antiretroviral medication over a nineteen-month period with my CD4 count then being 40.

The colonoscopy/endoscopy went ahead as scheduled on 30 May 2006 and those revealed my second AIDS defining opportunistic infection in eight years. This was severe candida oesophagitis involving the upper and middle oesophagus. My symptoms resolved relatively quickly after an immediate course of the anti-fungal drug Fluconazole and fortunately, there was no evidence whatsoever of either KS or MAC infections. Once again, my troublesome symptoms were blamed in part on my HIV antiretrovirals and very low CD4 count.

Unbeknown to me at the time, Dr Allen was so concerned about my declining health state, that she contacted a colleague at St. Vincent's Hospital Immunology B and Ambulatory Care (IBAC) unit, who several years earlier had done a HIV Registrar placement at HSC to see if I could be reviewed and/or suitable for any HIV antiretroviral drug trials that were happening at St. Vincent's at the time.

Consequently, I had my first appointment with Dr Sara Pett on the 8 June 2006 when my CD4/VL counts was 22/451,000. Sara and I had an immediate rapport, and nothing was too much trouble for her. I came to Australia when I was three years old in 1958 and both of us being born in England might have had something to do with this. She was amazed when I walked into her office armed with my own complete HIV antiretroviral medication and results spreadsheet which covered my complete thirteen-year HIV history.

Sara successfully secured me one of the last places available in the two-year MK-0518 (Raltegravir)/ placebo double blind trial in combination with boosted Darunavir, Ritonavir, Truvada and my old friend AZT which I had not taken since 1997.

My results over the next six months were nothing short of amazing and according to Sara, I experienced a 'phenomenal immune restoration' because of my change in HIV antiretroviral therapy on the study. She felt sure that I must have been on the non-placebo Raltegravir because I had done so well on the study. If I had have been on the placebo Raltegravir, this would have not been expected with the amount of HIV virus resistance I had. Despite successive trending undetectable viral load counts, Sara was not optimistic that my CD4 counts would ever get as high as 500. Because I was locked into a two-year drug trial and doing remarkable well from the outset, I transferred my HIV care to Dr Sarah Pett and was extremely grateful for her care and ongoing support.

2007: Blaming HIV antiretrovirals, water works and bad bones

Sixteen months after starting the MK-0518 trial, Sarah sent me for a thoracic spine x-ray because at the time it reported that people taking Truvada were experiencing a decrease in their bone mineral density.

At that stage I had been taking Truvada since May 2006 (when seeing Dr Boyle). I was very surprised when Sarah rang me in November 2007 with the bone density result, which revealed that I had a definite compression fracture at T7 and possibly at C6. I had not experienced any back pain or trauma. Sarah went on to tell me that I was borderline for having Osteoporosis (or in other words, Osteopenia).

I was referred to Dr Yvonne Selecki who was a specialist at the Bone and Mineral Research for the Garvan Institute of Medical Research. Initially I treated with Actonel Combi and my ongoing management for Osteopenia was transferred to my local GP. For the next five years I was treated with Actonel Combi and Caltrate before my GP suggested I was eligible to treated with a once-yearly infusion of the drug Aclasta. I changed GPs five years later and continued with the infusions annually until my GP decided that I had been on this medication too long and needed to have a break. I did what I was asked to do, and my GP wouldn't authorise a new script for Aclasta a year later until I had a long overdue Dexa Scan.

A follow-up scan at St. Vincent's in February 2022 revealed that my bone density had improved however, I was still classified as having Osteopenia. Unfortunately, I'm no longer eligible for yearly infusions and so am being solely managed by taking Caltrate alone. I must wait until age 70 before being eligible for other treatments that don't cost the earth.



On top of this I was experiencing nocturia and was referred to a local Urologist, Dr Mark Louie-Johnsun who diagnosed me with Benign Prostatic Hyperplasia (BPH). All other tests for prostate cancer were normal. I was prescribed the drug Flomaxtra which helped my nocturia, but did not reduce the size of my enlarged prostate. At the time a surgical possibility was discussed, and I chose to remain on the medication for as long as I could. A couple of years later my medication was reduced however, surgery became necessary twelve years later in 2020.

There have only been four 'blips' on my V/L radar in the sixteen years since I first walked into Sara's office. These only needed very minor adjustments to my HIV antiretroviral regimens by replacing AZT, Tenofovir and Truvada with 3TC and Etravirine. I have remained on the same regimen (five medications/nine pills daily) for the past eight years. A far cry from my very early disastrous treatment journey. I feel envious of those of you that can tolerate monotherapy, I believe that for me, 'it is what it is'.

2008: 'On the buses'

In mid-2008, HSC introduced a male specific after-hours sexual health clinic for men who could not get to the clinic during its regular operating hours. This was staffed by Michael Williamson (Registered Nurse) with administration support by me on Thursday evenings.

This clinic was very popular with men, especially those that commuted for work to either Sydney or Newcastle. Julie Asprey and Cindy O'Casey from our HIV/Sexual Health Promotion Team very successfully organised advertising with signage taking up the complete lengths of one side each of two Busways buses servicing routes around the Central Coast. The signs featured an Indigenous male running with the caption 'Gosford Guy's Clinic - Run in for a sexual health check up'.

Julie, Cindy and I worked collaboratively with the rest of the HARP Team two years later when I joined the PSN, and Julie was also a volunteer on the PSN Board for several years before that and beyond 2010.

2010: Time to jump ship

Because my HIV treatment plateaued in 2010, and life generally was good, I was once again thinking of reducing my work hours which at the time had crept up to 88 hours a fortnight since the introduction of the Thursday evening Guy's Clinic. Fortunately, with time-in-lieu (TIL) and monthly ADOs, this relieved some of my stress. Despite this, I suddenly found myself itching to do something new because I'd achieved everything I needed to do in my position at HSC.

At age 55, I qualified for early retirement on 5 January 2010, but wanted to still work part-time if I could.

This was not possible to do at HSC and when the PSN advertised for a new Manager in May 2010, I applied. My application was successful and a month later in June 2010 I began employment as the sole employee/manager.

Effectively I did semi-retire as the position was initially 25 hours/week over four days and the organisation's Board approved my request to work three days/week doing longer days. By the time I joined PSN, people living with HIV were living longer due to improvements in HIV antiretroviral medication and were less reliant on the organisation's care and support services.

Despite having an ongoing triannual funding agreement with NSW Health, often it was difficult to make ends meet. I worked hard with the Board and volunteers to revitalise programs and activities that formed part of that agreement while also improving community development and HIV health promotion in collaboration with the HARP Team.

Fortunately, the Positive Speaker Service was not affected and continued to enjoy ongoing success and was very popular with Central Coast High Schools which I wanted to continue supporting.

One of my first tasks was to complete arrangements for PSN/HUGS (HIV understanding and group support) annual retreat in September that year at Mary McKillop Educational Centre in Kincumber. I first visited this wonderful facility in 2000 when I was the Positive Life PSB co-ordinator. I had been invited to do a talk to members who were at the time doing a series of workshops at the retreat.

My talk was not about living with HIV, but instead it was about the PSB project. The group were very enthusiastic and excited to hear that people living with HIV in Sydney were travelling the state telling their personal HIV stories. I returned to the Mary McKillop venue in 2002 when I took a group of PSB positive speaker trainees there for a residential training weekend.

The next huge change was re-locating from PSN's rented premises at Point Frederick, to accept an offer from the then Northern Sydney Central Coast Health Service

(NSCCAHS) HARP Manager, Graham Stone to move into (and rent) office space, sharing the facilities with the HARP Sexual Health Promotion Team.

This arrangement saved the PSN scarce funding which then could be put to other services for local people living with HIV. HUGS was fundamentally PSN's core group of support and was still hugely popular, so activities were outsourced to keep that going. This was very successfully done and PSN enjoyed supporting the community more fully. I enjoyed sourcing funding from outside of the NSW Health funding agreement and doing fundraising events with the Board and volunteers.

A sizeable grant from the Sydney Gay and Lesbian Business Association (SGLBA) towards the end of 2010, was my first big success and ensured financial security for PSN activities for quite some time.

Towards the end of 2010 I hosted a group of TAFE students who were doing their Certificate 4 in Mental Health and their teacher, Carol Huggett, at the newly acquired PSN office in Ward Street, Gosford. Students were doing Community Services and NGO agency familiarisation, and over the next five years I hosted many such visits.

I somehow managed to find the time over the next four years to then go on to volunteer my time doing TAFE course validation as an 'Industry expert'. Consequently, I was head-hunted to become a part-time casual teacher for TAFE NSW in 2015, after obtaining my TAE qualification. Carol joined the PSN Board in 2011 and remained as Secretary until the Board elected to close the organisation permanently in December 2015 after almost 25 years' service for Central Coast people living with HIV (more in Oct '22 Talkabout).

By the time this edition of Talkabout is published I will have clocked up another year as a positive person (29 years).

In the next edition I will write about the period 2011–2016, back to the future, Sara's return to UK, PSN Red Event, HAND, four-day cruise to nowhere, AIDS 2014 Melbourne, billboards and time capsule, adult education and myocardial infarction.

– Paul R Maudlin OAM, JP

MOVING TOWARDS DIGNITY

With the pandemic and the challenges and uncertainty of an ever-changing world, I have reflected upon the last 15 years since my HIV diagnosis; a journey with its own challenges and uncertainties as well.

When I was newly diagnosed, I felt guilt, anger, depression, and shame. I instantly questioned my choices and decisions leading up to contracting HIV. The HIV stigma and prejudice that is rife in our society only further compounded my self-judgemental feelings.

I found it difficult to move beyond the little voice in my head that berated myself and repeated the nasty comments many of us living with HIV have heard before.

I realised, I must be kind and forgiving to myself, in relation to living with this chronic condition. The words 'HIV' and 'virus' often bring forth a lack of forgiveness and an unkind attitude towards ourselves.

HIV is contracted, not developed like other chronic conditions. Yet, as HIV is contracted based on one's decisions and actions, so can heart disease and many other health related chronic conditions, developed because of one's previous decisions and actions. In the end, most health conditions are chronic because of something.

Living with HIV carries with it the typical stigma that is a continuous personal battle for all of us, and part of this journey. Yet, so what? I have HIV.

This chronic condition helped me to rediscover myself; in realising my dignity, self-worth, and identity as a person.

Like any other medical condition, it doesn't define who I am, what I can do, and what I plan to do. Chronic illness unfortunately is part of being human.

Are there moments when it hits me like "wow, I have HIV?" Absolutely. I never forget, but I live my life to the fullest.

This is why I believe living with HIV helps to keep you mentally and emotionally grounded in what is truly important; as it gives you motivation and insight to live your purpose, use your talents, and achieve your dreams.

Like many of us, I have been truly fortunate to benefit from the breakthroughs in HIV treatment. That being said, like others, I too live with the challenges of living with HIV; in regards to comorbidity, treatment, and general health related issues that may arise, other than comorbidity; due to the everyday living with HIV.

Having lived with this condition for fifteen years, and as difficult as it may seem at times, this is my reality in the great life I have. What doesn't kill you only makes you stronger.

I am happy. Life is good and a blessing, even with HIV; something that must never be forgotten.

– James Cotromanes



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Women living with HIV and Anal Cancer

As women living with HIV, it is important we are vigilant about our health.

Human Papilloma Virus (HPV) is a silent sexually transmitted infection (STI) that 80% of us will contract through sex. The majority of us won't know we've got it and usually it clears itself without any medical treatment.

So why is this such a big risk for those of us living with HIV?

HPV has the risk of causing small cell changes, called precancers, which can go on to develop other types of cancer in the cells of the vulva, vagina, cervix, anus and even the throat. It is strongly recommended that all women living with HIV, get regular cervical screen tests (CSTs).

Having a regular cervical screen test can detect HPV and any abnormal high-risk changes. This means you have the best chance of detecting any HPV-related cancers early.

If HPV is detected, then it is worthwhile to discuss an anal screen with your doctor.

The biggest risk for women living with HIV who develop anal cancer, is thinking anal cancer doesn't apply to us.

Anal cancer has nothing to do with having anal sex. It is caused by the human papilloma virus itself. Women who have had an abnormal cervical screen are about five times more likely to develop anal cancer compared with the general female population.

While there is no treatment for HPV, there are various vaccinations available, which are effective in preventing anal HPV infection before the development of precancer lesions. The most common vaccine is given to young people, ideally before they are sexually active. With more than 100 strains of HPV, even if you have had the HPV vaccine, not all strains are included.

Unfortunately, women living with HIV are 15 times more likely to develop anal cancer compared with the general female population. Early detection means early treatment. Early treatment is your best chance to treat anal cancer quickly and effectively or even prevent it.

If you're a woman living with HIV and want more information about HPV or anal cancer, you can call Positive Life on (02) 8357 8386, 1800 245 677 (freecall) or email contact@positivelife.org.au to speak to another woman living with HIV.

– Kim and Priscilla



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

- 
- SEPTEMBER**
- 6 **Positive Conversations 6pm Online**
For all people living with HIV
 - 9 **Social Club Sydney 6pm**
For all people living with HIV who identify as heterosexual
 - 13 **For Women 6.30pm Online**
For all women living with HIV over 45 years of age
 - 15 **[+Connect] Camperdown 7pm**
For all people living with HIV, our partners, friends and family
 - 21 **Digital Mentors Sydney 12.15pm**
For all people living with HIV
 - 22 **Peers Connect HNE 12.30pm**
For all people living with HIV

- 
- OCTOBER**
- 5 **The Men's Room Sydney 6pm**
For all men living with HIV who identify as heterosexual
 - 7 **Social Club Sydney 6pm**
For all people living with HIV who identify as heterosexual
 - 11 **The Women's Room 6.30pm Online**
For all women living with HIV under 45 years of age
 - 13 **In The Know 7pm**
For all people living with HIV
 - 18 **Positive Conversations 6pm Online**
For all people living with HIV
 - 19 **Peer2Peer Sydney 6pm**
For all gay/bisexual men living with HIV
 - 26 **Digital Mentors Sydney 12.15pm**
For all people living with HIV

- NOVEMBER**
- 4 **Social Club Sydney 6pm**
For all people living with HIV who identify as heterosexual
 - 8 **For Women 6.30pm Online**
For all women living with HIV over 45 years of age
 - 15 **Positive Conversations 6pm Online**
For all people living with HIV
 - 17 **[+Connect] Ultimo 12noon**
For all people living with HIV, our partners, friends and family
 - 24 **Peers Connect HNE 12.30pm**
For all people living with HIV
 - 30 **Digital Mentors Sydney 12.15pm**
For all people living with HIV

In My Own Words

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Event details are correct at time of printing.

Keeping a healthy mouth gives you a fabulous smile, fresh breath and makes the food you eat even tastier. Good oral health helps protect your

body against infection and other conditions like heart disease and diabetes. Many people living with HIV experience changes in their oral health and there are many ways to keep your mouth happy and healthy.

Teeth are not only important for chewing but healthy teeth support good nutrition and looking your best.

Brushing your teeth at least twice a day will help reduce dental decay. Two major oral health conditions, decay and gum disease, are both caused by bacteria which grows on everyone's teeth every day (known as dental plaque). Brushing and cleaning between your teeth helps to remove these bacteria from your mouth.

So, what can you do right now to keep your teeth and mouth healthy and have a magnificent smile?

1. Firstly you can do an Oral Health Self-Assessment by asking yourself:

- Has it been more than one year since you have been to the dentist?
- Do you have tooth pain, mouth sores, bleeding gums or loose teeth?
- Do you often have a dry mouth or experience a change in your sense of taste?

You need to see a dentist if you answer yes to any of these questions. Note: if you have dentures, you will definitely need a dental check.

2. Secondly, ask your health professional for advice on keeping your mouth healthy.

Don't wait until there is a problem. Regular dental check-ups take care of any dental issues proactively.

3. Clean your teeth at least twice per day.

Water and mouthwash will not remove dental plaque. A brush is needed to clean away these bacteria. Brush your teeth slowly for at least two minutes every time with a small head toothbrush with soft bristles. Use a small amount (about the size of a pea) of fluoride toothpaste for all natural teeth. Fluoride replaces the mineral that plaque and food acid removes.

It's important to clean between your teeth with an interdental brush or floss every day before brushing your teeth. Ask your dentist to help you select the best size interdental brush for you. If you use a mouthwash, use this after brushing.

If you have dentures, keeping them clean is also vital for good oral health. Don't use toothpaste to clean denture teeth. Clean or rinse your denture after every meal. Remove full and partial dentures before going to sleep. This will allow your gums to be bathed in saliva overnight, which is protective for your mouth.

4. Eat well and drink plenty of tap water.

Food is to be enjoyed. What you eat and drink also affects your mouth and teeth. Your mouth loves water and sipping regularly through the days helps to wash away sugar and acids left by our food and drinks.

It's not always easy or practical to completely cut out all foods that contribute to tooth decay. Knowing some basic facts about tooth-friendly eating and drinking habits can help you to maintain a healthy mouth.

- Eat a variety of foods including; whole grains, fruits, vegetables, sources of lean protein such as beef, chicken, and fish, dried beans, peas and other legumes such as baked beans, and dairy foods such as milk, yoghurt and cheese (include at least 2-3 serves each day as these are protective for your teeth).
- Limit the number of snacks you eat. Frequent grazing can increase dental plaque.
- Choose healthy foods to snack on like fresh fruit, yoghurt, raw vegetable sticks or soups, unsalted nuts or cheese.
- Eat a meal that includes crunchy fresh food if you choose to eat high sugar or sticky foods such as lollies, chocolates, cakes or biscuits. Make sure you also drink water with this food.
- Avoid having acidic foods last thing at night e.g. fruit, pickles or even chewable vitamin C tablets.
- Carry a water bottle and sip water throughout the day.
- To keep your mouth moist, try to drink water every time you drink tea, coffee or alcohol (these drinks can make your mouth dry).
- If you have a dry mouth, chewing sugar free gum and eating hard foods like raw vegetables and fruits like apples can help increase saliva.

5. Quit smoking or seek treatment for tobacco dependence.

It can be hard, but it is one of the most rewarding things you can do to improve your overall health, including your mouth. Smoking can make gum disease harder to detect at the same time as making it worse.

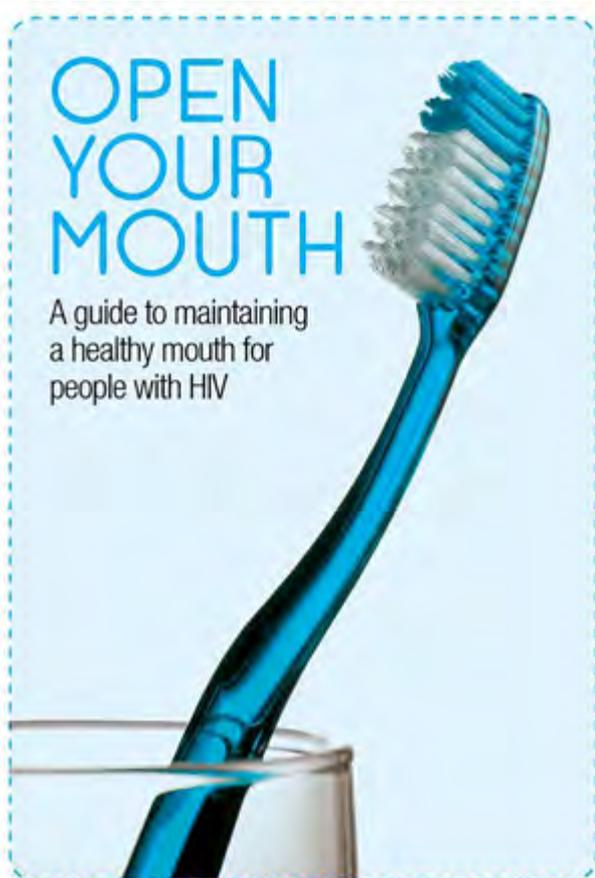
When you stop smoking you are less likely to have bad breath, stained teeth and a stained tongue. Talk to your health professional or call the Quitline 13 78 48.

For more information visit the [Open Your Mouth booklet](#) on the Positive Life NSW website.

For information on financial assistance or subsidised dental services, visit '[Find a Dentist](#)' on the Positive Life NSW website or contact your local hospital or clinic.

An Albion Centre Dietitian can also offer you advice on eating and healthy diet for your mouth. Call (02) 9332 9600 or search for a dietitian at <https://member.dietitiansaustralia.org.au/faapd>

– The Albion Centre Nutrition Team



Acknowledgement to the Oral Health Promotion Working Group's "Open your Mouth" resources which were produced in Partnership with NSW Health HIV services, Sydney Dental Hospital, Positive Life NSW, ACON and BGF and used in the production of this article.





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