

IN MY

OWN WORDS

AMBUSHED

TELLING MY KIDS

FROM THE HOSPITAL BED



EDITION #210

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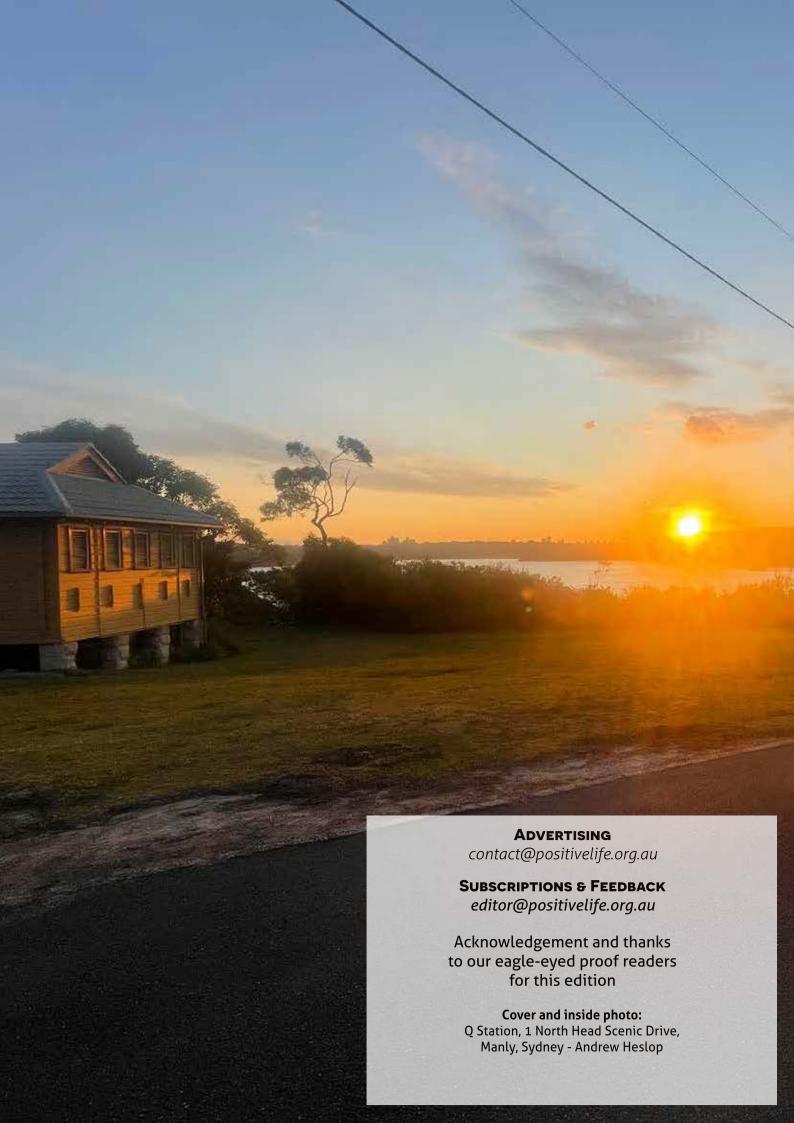
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BLUE PENCIL

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

With a strong medical theme, in this edition Kim reflects on her personal experiences and advocacy in 'From the Hospital Bed' (page 8), and Maria shares her thoughts on the strategy all people living with HIV can use to form a strong alliance with our doctors in 'What I want in a doctor...' (page 16). The Talkabout Advisory Committee as a group offer a suggested list of things to pack if you're planning or preparing for a hospital visit (page 10).

Kim shares her play 'Ambushed: A play of sorts - a tragicomedy' which highlights the very real experience that many women living with HIV experience during their interactions with the medical system (page 14-15).

In other features in this edition, Positive Life NSW caught up with PSB Speaker and Board Member Melissa and her children to hear their thoughts and reflections as a family when Melissa decided to disclose she was living with HIV (page 12).

Long time writer and Talkabout Advisory Group member, Tim Alderman continues sharing his 40 year journey into (and out of) fear on page 22. He shares a further reflection on being a long-term HIV survivor of 40+ years (page 18).

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

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

Call me on (02) 8357-8386 or 1800 245 677 or by email on contact@positivelife.org.au. I look forward to hearing from you in the near future.

CRAIG ANDREWS EDITOR

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Secondly, I would like to welcome Roberto Fabbiano to the Positive Life NSW team. Roberto is our new Peer Support Officer in the peer navigation team. His work will focus on supporting all people living with HIV. I wish him all the best.

At recent NSW Health symposiums and workshops organised in Greater Western Sydney, the valuable and life-changing work that our Positive Life NSW Peer Navigators, Billy and Priscilla are doing was highlighted. This work takes place in-clinic at Western Sydney Sexual Health Centre, Liverpool Sexual Health Centre and Liverpool Hospital Immunology Department. Engaging with the community as they attend clinical appointments has proven exceptionally beneficial for the communities of people living with HIV in Greater Western Sydney and our peer navigators work and impact has been highly praised through these sexual health and clinical departments, as well as by HIV and Related Programs Units and the Ministry of Health. Well done to both of you and to all the team for their fantastic work.

I would like to congratulate the Bobby Goldsmith Foundation who are the winners of this year's ACON Honours HIV Hero Award. It was a privilege to present this honour at the event on behalf of Positive Life NSW. I would also like to acknowledge the other categories winners and the two other HIV Hero nominees - Dr Shih-Chi Kao and Stephen Allkins.

The upcoming Board nomination and voting period is nearly upon us again with our AGM and end of year gathering to be held on Wednesday 4 December. I encourage all Positive Life Full members who might be considering putting in a nomination, to come along to the Members Information Session. Keep an eye out for details which will be sent by email to all Positive Life NSW Full members regarding this in the coming weeks.

Finally, I would also like to acknowledge the sad passing of our friend, Positive Life founder and giant in the HIV sector, Bill Whittaker. Throughout his distinguished career, Bill held pivotal leadership roles in key organisations. His ongoing commitment to enhancing the quality of life for those living with HIV was exemplary. Bill will be deeply missed yet his legacy will always stand strong.

Go Well and be Kind to each other

STEPHEN LUNNY **PRESIDENT**







LIVING WITH HIV AND FINDING IT DIFFICULT TO CONNECT WITH SERVICES AUSTRALIA?

All people living with HIV who are finding it difficult to contact Services Australia (Centrelink, Medicare etc), are invited to get in touch with Positive Life NSW to make a face-to-face appointment with a Services Australia Officer on (02) 835708386 or email contact@positivelife.org.au

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

POSITIVE IMPACT WORKSHOP

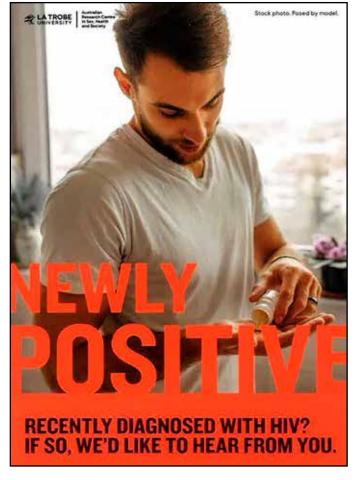
Positive Life NSW ran a residential workshop for people living with HIV who identify as heterosexual or bisexual over the weekend of 13-15 September 2024. The workshop focused on developing a range of innovative HIV prevention strategies for heterosexually identifying and bisexual people, including those from culturally and linguistically diverse backgrounds, who are overseas-born and reside in Greater Western Sydney. The outcomes will be developed into a report for the NSW Ministry of Health to be used to inform future HIV testing and prevention campaigns, and strategies designed to reach populations who have not been served by current HIV prevention messaging.

COUNSELLING SERVICE

The Positive Life NSW pilot program, *Positive Minds* has been operating to capacity since it began in June 2023. All people living with HIV across NSW are eligible to use this dedicated mental health and counselling service free of charge. *Positive Minds* offers counselling services within a safe, supportive, person-centred approach by two accredited, qualified and trained counsellors, both of whom are either living with HIV or directly affected by HIV.

To discuss your needs and participate in a confidential initial intake process, all people living with HIV across NSW can call Positive Life NSW on (02) 8357 8386, 1800 245 677 (freecall outside metro areas) or email contact@positivelife.org.au

TALK SHOP





A hospital stay can be an overwhelming experience.

Being in a different environment, not knowing what to expect and not fully understanding the treatment being given, are just a few reasons why it is common for people to have feelings of uncertainty, anxiety and vulnerability.

Other reasons that a hospital stay may be overwhelming include feeling overloaded with information, having to make decisions about healthcare, and having to put your trust in health care professionals.

Knowing what to expect can make a hospital stay run more smoothly. I have had various stays in hospital and although they may have different processes, there are some general similarities.

I have been admitted to hospital after going to the Emergency Department. Some things that I've been glad to have taken with me to the Emergency Department are my antiretroviral medications, my phone and charger, and something to pass the time like a book or a crossword.

In my experience, the wait in Emergency Departments can be extremely long. Personally I don't mind the wait because when it is my turn, I have always found the medical staff to be extremely thorough.

A triage nurse will usually see patients within a reasonable timeframe and assess their condition. Then depending on the needs of the patient they may see a Nurse Practitioner or a series of doctors who give options on the next steps.

Sometimes, I have been admitted to hospital because I have had a planned surgery booked. Before the surgery there is a pre-admission process. This can be either at a clinic or as a phone consultation and may include seeing different specialists such as an anaesthetist and/ or a pharmacist.

I find the pre-admission process a great opportunity to bring up any concerns or needs I may have. One specific concern for people living with HIV may be the importance of taking antiretroviral medication consistently and how to ensure this will be administered correctly. Another concern for people living with HIV regarding their hospital stay may be patient privacy.

On the day of the surgery, there are usually more questions to answer. I always think the more information I give the hospital staff, the better the treatment I will get. However, there have



been situations when I haven't answered questions, especially if I'm feeling uncomfortable and instead I've used phrases like 'How is that question relevant to my healthcare?'

I have found on the whole that medical staff have been reassuring and have guided me through the whole process.

Afterwards, I have woken up in a recovery room, then I've been taken to a ward. Wards may have lots of other patients and feel like a big long hallway, or sometimes have 2, 4 or 6 beds in a room. Once I had a room and bathroom all to myself.

In the ward, nurses do observations like checking temperature and blood pressure and they administer medication. My antiretrovirals have generally been popped in a locked drawer near my bed and the nurses take them out and give them to me when needed. They document when I take them so that they can have a better idea of what is going on for me. There's also a buzzer beside the bed to call the nurses. I was hesitant to use the buzzer at first as I didn't want to bother anyone. But the nurses are usually more than happy to help.

Advocating for myself in hospital can be difficult. If anyone in hospital is lucky enough to have family members or friends to support them during their stay, then definitely call on them.

If a serious situation arises that needs to be dealt with immediately, then you can ask to speak to the Nurse in Charge. A Nurse in Charge is usually more apt at dealing with difficult situations and providing a suitable outcome and will escalate the issue if needed.

Anyone who has serious concerns regarding their treatment or experiences worrying changes in their condition, and needs urgent action to be taken, can start a process called REACH. This is a method that helps patients, carer/s, and families to escalate their concerns with staff about worrying changes in a patient's condition. It stands for Recognise, Engage, Act, Call, and Help. In Queensland a similar process is called Ryan's Rule.

When leaving hospital, anyone who needs transport to get home or help at home then I would suggest letting the nurses know before your discharge, or ask to see a Social Worker. It may take some time to organise so the sooner the nurses know, the better.

I have been quite exhausted after a stay in hospital and my recovery always seems to take longer than I imagine. But with rest and patience, I do get back to my old self.

- Kim



Then you're planning for a hospital visit, the 2024 Talkabout Advisory Committee offers the following list of what you might want to pack.

- Talkabout Advisory Committee

- Paperwork such as Medicare card, health care concession cards, seniors card, GP details and private health insurance if applicable
- Current Medications
- Phone, charger. earphones, noise cancelling headphones
- Loose clothing, comfy nightwear, slippers, dressing gown, jumper, warm socks
- Toiletries such as hair brush, hair ties, hand cream, face cream, lip balm tooth paste, toothbrush, hair brush, sanitary items
- Health aids such as hearing aids, false teeth, glasses/ glasses case, magnifiers, dentures, Polident
- Something to pass the time such as a book or crossword, pen and notebook
- Favourite Snacks
- Try not to overpack as wards may not have too much room
- Some money but try to leave valuable items at home
- Arrange transport to and from the hospital



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 areas of law as: privacy, discrimination, immigration, end of life planning, insurance, superannuation, social security, criminal, family, housing and more.

For confidential legal assistance please contact us: Phone **02** 9492 6540 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



Contact Positive Life
02 8357 8386 or 1800 245 677 (freecall)

Positive Life NSW



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

Life NSW recently sat down with PSB Speaker and Board Member Melissa and her two children, Amari and Johannes*. They shared their thoughts and reflections since learning from their mum that she's living with HIV.

I decided to talk with both my kids in May last year, said Mel. It was a Thursday night. Just the three of us went out for a casual dinner. No family. I started the conversation with telling both of them, "I have something to tell you." Then I said, I have HIV."

Even though Mel was diagnosed with HIV three years after the birth of her second child, son Johannes, she delayed sharing the news with both of them for another nine years. Supported by her parents and closest relatives, she wanted to wait until they were able to understand and discuss the news.

She says, I don't think they were that surprised. I'm pretty sure my daughter Amari already knew. They asked the usual questions like, where, how and what kind of questions. I expected these.

16-year-old Amari interjects, "I knew already. I could tell," she said. "I knew a few things about HIV, and I could tell my mom was taking medication daily. I knew this was something that people living with HIV do to, you know, keep themselves safe from the virus."

Besides learning a little bit about HIV at school, Amari had also noticed the phrase "people living with HIV" on a banner at a Positive Life event the family had attended. Mel says, "even though I thought she might have known something, she never really asked me directly, so I didn't push myself to talk about it with her straight away."

Mel asks her daughter, "how often are you learning about HIV at school? Do they teach you that people can live a long life with HIV? Or did you think you can die from it?"

* Not their real names

"Well, I'm doing PDHPE at school, and there's a health unit," said Amari. "We also go through contraceptives and STIs." PDHPE, or Personal Development, Health and Physical Education is a mandatory NSW Education from kindergarten to year 10 which provides students with the knowledge, understanding and skills to enhance their own and others' health, safety and wellbeing.

At the time, Mel says 13-year-old Johannes asked "how did you get it?" Without too much detail, I explained that I made a decision when I was younger, and got it from somebody through unprotected sex.

I think one of them asked me how long I've had it, or where did I get it? I shared with them I was diagnosed with HIV after we came to Australia. Then I took them on a journey about our life since then, including coming into contact with Positive Life NSW and getting support from other people who also lived with HIV.

After we started coming to Positive Life events, I remember one time they asked me, "why do we come to these events?" At the time, I wasn't ready to share my diagnosis with them, so I was vague and said something like 'it's just, you know, to be positive, like for depression.' They were like, "yeah, all right" and didn't ask more questions.

Mel reflects, "that night at dinner, after I told them I have HIV, we talked about it a little bit more, and then it was just like, so how's the weather?

"It was very normal," said Mel. "I think I've been really lucky, or maybe because they'd been with me to so many Positive Life events, they could see I was gonna be okay. It wasn't a fearful thing to tell them or anything. It was more just like, ah okay."

"I just know that you're in good hands," says Johannes. "Your medication is gonna keep you alive and well. I know nothing really bad is gonna happen. You're in good hands."

"What do you mean, I'm in good hands?" asks Mel.

"Like you're still the same, okay, just living a normal life," answers Johannes. "Your medication, your doctors, they're helping you. Your friends and stuff."

"I don't really think or worry about it," says Amari. "I honestly forget that you have it. Like it doesn't really affect your day to day life."

She hesitates, "I mean, yeah sometimes, when you get sick. I know your immune system is a little bit weaker, so it's definitely a thing to look out for. If I have questions, or if I learn something at school and I want to clarify, I know I can just ask you right?"

They also wanted to know who else knew about my HIV, says Mel. I told them that my parents, their grandparents knew. My brother knew. A few of my close friends knew. They'd been with me many times in hospital waiting rooms, so I talked about the support and care I already get from the hospital and my doctors.

I also shared with them about being on the Positive Life Board and how that's connected to me living with HIV. As a Black woman, I especially want to inspire other black young women who might be living with HIV. They know I feel that it's very important for people of colour to be seen in positions of influence and authority, especially as company directors on boards.

Since starting as a speaker with the Positive Life Speakers Bureau, I've had a number of conversations with my kids about what that means and what do they think about my work as a speaker. Understandably, they both have concerns about the impact of HIV stigma in the community and discriminatory attitudes about HIV or about people who have HIV. At this time, they have slightly different views about this. Amari thinks it would be cool for me to speak at her school to provide a different perspective on HIV, while Johannes is a little more cautious and concerned about the lack of education. So we've agreed to wait until they both graduate before I do any school presentations.

"Why did you wait this long to tell us?"
Johannes asks. "Were you planning on waiting a little longer, like when we're 18 or 20?"

"Good question," responds Mel. "I was always going to do it when you guys were like 18 and 20. I always had that in my mind. When I told you last May, you would have been 15 and 12. I think it was I just found the right moment, and I thought, you guys are mature enough to talk about it now. I think your maturity just kind of made me want to tell you sooner as well in all the things that I've been involved with.

"Do you feel better now that you know, or does it really not make a difference whether you know or not," asks Mel. "It's less mysterious, now," says Johannes. "Less mysterious."

"What advice would you give other women who want to tell their children about their HIV," asks Amari.

Mel laughs. "I can't give a hard and fast rule," she answers. "There's no definite rule, like tell your kids at 18, or 13. No. I think the right time is more about the maturity level of the child and how they're doing mentally as well. I would not have told you guys if one of you were struggling in school or have a problem with a friend, or if we're arguing at home. You know what I mean."

"The only thing I'd say is just know your child, know you'll know in the right time. Don't force it. But also not telling you was not detrimental to you guys. You still lived with me, you still went to school every day. We have a beautiful life. So yeah, it's just knowing your child. And I know you guys, I think I know you guys now."

"I'm really lucky that my children are, I suppose, educated about HIV," says Mel.

"I know that they are a minority, because not everybody has a parent living with HIV. I'm lucky that with any knowledge they learn about HIV, they can always cross reference it with me, and if I don't know the answer, I'll can lean on my doctors, my healthcare team or Positive Life NSW.

Foreword: The characters did not actually say the words I have attributed to them. Whatever words they did use are completely immaterial. The words used in this play are the words that I heard. Heard from their tone of voice, their body language and their demeanour. These are the impressions that they made upon me at the time and I have carried these with me for 14 years.

Dramatis Personae

The Specialist

The Junior Doctor

The Nurse

The Counsellor

The Patient - (me)

The Mother

Scene: A narrow doctor's office. The patient (me) is seated uncomfortably in the middle of the room. The junior doctor is also seated. The nurse and the counsellor are leaning on the hospital bed. The specialist enters and sets himself down in the seat beside the office desk.

The Patient (me): Hello, I have come along today to get a prescription. (Aside) not sure why this feels like a job interview?

The Specialist: Oh yes, yes, I'll deal with that at the end, I insist on taking control of this appointment

and am going to disregard your request for a prescription until the very end, that is, if I even remember.

Now, you've only been recently diagnosed, and I know that anyone with even a fraction of a heart would want to reassure you that, although you are feeling overwhelmed and vulnerable right now, you are in good hands. But no, not me, no siree, no show of emotion here, what would my colleagues think!

Instead, we have a list of generic questions to make you feel like less of a person and more of a statistic. We have especially sought out questions that perpetuate the stigma and the myths attached to HIV. We also don't try and establish any kind of rapport with you beforehand or consider explaining why these questions are relevant to your healthcare. It is imperative that you give us answers straight away, because how else are we to make judgements about you and file you into the proper category without them?

We also feel it is our duty to not use any sensitivity or tact, whether it is in front of your mother or not. Oh, that's right we had quite forgotten about her.

Spotlight falls on an older lady perched on a chair in the corner with her handbag sitting neatly on her lap.

The patient (me): (Aside) Yes, that's mum, isn't that a chair that's used in Primary School? At least she has a chair I suppose, the other two, the nurse and the counsellor don't. Why don't they have enough chairs? It's quite unnerving the way they are looming over me.

The Specialist: What's your sexuality?

The Patient (me): Heterosexual.

(Aside) Why is this important? Oh, it must be the same generic list of questions they use to discriminate against male patients too?

The specialist: **Are you an intravenous drug user?** The patient (me): **No.**

Aside: I want to say 'prefer not to say' but that's just another way of saying 'Yes' isn't it? But I'm not, so I feel I have to say no. But I don't want to.

The specialist: Have you ever been paid for sex?

The patient (me): No.

Aside: How embarrassing! How could he ask me that in front of my mother? I can see her cringing and squirming from the corner of my eye. Look, she's mortified. I wonder what imprint these questions are making on mum's view of me?

Anyway, sex workers are much more switched on when it comes to sexual health, so if I had been paid for sex, I probably wouldn't be sitting here in front of this jury.

The Specialist: How did you contract it?

The panel of judges turn and glare at the Patient (me).

The patient (me): Through sex.

(Aside) Not something I particularly want to share with you all, but I just want this to end. Please just finish.

The Junior Doctor: That's not very juicy. Boor ring.

The Specialist: How many sexual partners have you had?

A look of gleeful suspense crosses the faces of the Junior Doctor, the Nurse, and the Counsellor.

The patient(me): (Aside) What? No-one ever asks lotto winners how many lottery tickets they bought before they won the big one, do they? It's of no consequence to anybody except for gossipers who engage in idle chit chat and tittle tattle.

The patient (me): Prefer not to say.

A sigh of disappointment is heard from the vicinity of the hospital bed where both the Nurse and the Counsellor are standing.

The Counsellor: Can't you see, we wanted the deets!

The Specialist: Well, we've got what we need from this appointment. We must wrap this up. Looks at the time on his Rolex watch. I'm going to be ten minutes late for morning tea as it is.

The Mother: stuttering quietly almost in a whisper, **The the pre prescription.**

The Specialist: The what? I can barely hear you over there?

The Nurse: She said the prescription.

The Specialist: Oh yes, that's right, here you go. Passes the prescription to the Patient (me) Morning Tea time now. The Specialist leads the way off stage. The others follow in good spirits discussing much more important matters as they go.

Junior Doctor: Nurse, don't forget to ring that other patient. Nurse: Yes Doctor, and can you sign that blood test for me?

Junior Doctor: Yes, of course, no trouble.

Exeunt: The Specialist, The Junior Doctor, The Nurse and The Counsellor.

The Mother and the daughter remain. They sit silently, blankly staring at one another in disbelief. They slowly gather their things and pick their guts up from the floor. As they leave the stage, the daughter holds her mother's hand ever so tightly with one hand and clutches the prescription in the other.

WHAT I WANT IN A DOCTOR...

Thave a good relationship with my current GP. It took time, a clear vision of what I wanted in a GP, determination, the dismissal of four previous GPs – one I had persisted with for ten years – and about 18 months without one.

During the years that I've lived with HIV I've gradually honed my self-advocacy muscles. In the beginning of life with HIV I didn't realise that this would be necessary. I had been lucky – I was healthy and fit prior to HIV making its grand entrance, so I only occasionally crossed paths with healthcare providers. Since then, I've learned the hard way that HIV-related-stigma and ignorance is alive and well within the health field.

HIV is not the only condition that requires a long-term relationship with one or more healthcare providers, nor is it the only one that is stigmatised. It does, however, carry a special kind of aura. Like many others, I have been on the receiving end of dreadful, judgemental, and sometimes downright aggressive behaviour delivered by healthcare providers. Fortunately, I have also come across some exceptional people working in the field. I will never forget those individuals and their capacity for engaging with genuine compassion, sensitivity, and a confident professionalism.

Like any healthy long-term relationship, the trust that is developed with HIV health providers takes time to build. It must start somewhere though – trust is built step by step, and by taking some chances. On first meeting my current GP, after giving her some background, I directly asked for what I wanted in this potential relationship. I also admitted that I would very likely challenge her at times! Our interaction was a mutually respectful and honest conversation.

She sat facing me and listened without interrupting, then spoke in response with a kind of unassuming clarity and intelligence. My 'gut feeling' about her was very positive and I decided to give her a go. Eight years down the track I feel very fortunate to have her as my primary care doctor. Trusting her means that I'm honest about my choices and decisions. I tell her stuff that I might have hesitated to tell other doctors. Her trusting me means that I have agency and choice regarding my health care.

We are all unique, and what fits for one might not for another. HIV both adds an extra layer of challenge and makes it vitally important to have a good fit with your healthcare provider. The 'therapeutic alliance' concept outlines three main components to a strong therapeutic relationship – a warm and respectful approach, collaborative goal setting, and working towards mutually agreed goals.

I've adapted the following from an article by Sarah Jacoby that quotes Dr F. Perry Wilson, Associate Professor at the Yale School of Medicine and author of "How Medicine Works and When it Doesn't: Learning Who to Trust to Get and Stay Healthy".

What makes a strong therapeutic alliance?

You feel like a team

- The relationship is a collaboration
- You are listened to and know that your concerns are taken seriously
- That is, your experiences, preferences, evaluations and opinions are considered.

They know the science and willingly share it with you

- They know, or can access, relevant information and can explain it to you
- Furthermore, if there are options to approaches and treatments, they can provide you with details, and pros and cons

They acknowledge uncertainties, and will admit to getting things wrong

- Healthcare providers are not infallible, and medicine is not an exact science it's complicated
- Sometimes things might have unforeseen effects, or just not work
- They have the flexibility to re-adjust, and to take your lifestyle and preferences into account

They accept your decisions about your health

- Sometimes you might disagree with them, or find that you are having challenges staying on track with a previous agreement
- A strong relationship built on trust should allow for disagreement and discussion without a negative impact on the relationship

The quality of any long-term relationship with a healthcare provider can either encourage or discourage engagement with healthcare. A strong relationship is a partnership and the more you trust your doctor and feel able to talk with them openly and honestly, the better the outcomes will be for you. One of those outcomes will be that you are actively involved and confident in your healthcare decisions.

Self-advocacy can be hard work sometimes, particularly at times of vulnerability, low energy, or if you're just not used to doing it.

If you want to discuss your options, or brainstorm ways to advocate for your needs with another person living with HIV, reach out to Positive Life NSW on 8357 8386, 1800 245 677 or email contact@positivelife.org.au

- Maria





o, how do I feel about long term survival? Initially...surprise!

I was late coming out as a gay man, I was 26, and temporarily living in Melbourne at the time. It was 1980. So when I seroconverted in August 1983, and realised that my life as a fairly newly out gay man who had only just started on his sexual journey, and as a HIV+ man, were going to go forward hand in hand, thus there was that moment of disappointment when I thought "Shit! Why did I leave it so long to come out!"

Well over two-thirds of my life has been lived as both a HIV+ man, and as someone who developed AIDS in June 1996. 41 years is a long time to live with anything, especially considering the two years that was predicted by doctors in Albion Street in the early days.

There was certainly surprise when, after the two years had passed...I was still hale and hearty, though rapidly becoming a one man smoke machine, and a potential alcoholic...a domain shared by many of us who had witnessed a lifetimes sorrow in a short space of time.. While all that was going on around us, we tried to maintain a semblance of normality, socialising, partying, a sex life...despite sex having become a little bit weird at that stage... and having relationships.

The latter was often fraught with sadness...I personally lost two partners over this period. Normality was hard fought for, as we were bombarded on a daily basis by those we knew being seriously ill, some dying at home, some taking their own lives, others passed away in hospital wards such as 17 South in St Vincent's, or in palliative care in places like the Sacred Heart Hospice, though always under the loving care of nuns, nurses, doctors, and support workers.

We attended funeral after funeral ad infinitum, until, burnt out, we could attend no more! Relentlessly heartbreaking, the deaths of so many we loved would leave a lasting impact on our lives. Of my social circle of over 60 close friends, by the time the deaths were on the decline, I could count the survivors on two hands.

A further surprise awaiting me was battling through until 1996 before the full effects of too much drinking, too much smoking, bad diet, overwork, stress, the absence of an immune system, weighing in at 48kg and dropping, and with 10 CD4s also dropping, which finally found me in a bed at Prince Henry Hospital's Marks Pavilion with chronic CMV retinitis and a raft of other problems. I went into Prince Henry fully expecting to die!

The probability of death was very high, with the only thing sitting between me and it was a new class of drugs just released called Protease Inhibitors. Despite coming with no guarantee...I'm here today, so they obviously worked.

Coming out the other end of that, there was a long and continuing roller coaster ride for over eighteen months to recovery. I won't overload you with that battle here.

The effects of this Lazarus Syndrome, this rising from the dead, so to speak, had profound consequences...in a positive way. In 1998, I wrote an article for Talkabout, titled "A Life Reset to Zero"...and that's exactly what it was. There was a life before AIDS...and a life after AIDS.

Now visually disabled, and mobility challenged, I made a very firm promise to myself that it was time to challenge myself for a very different future. This was a very empowering period of my life, pushed in many respects by surviving AIDS, university, TAFE, taking on writing and public speaking about the ups and downs of living through the HIV/AIDS pandemic, and starting my own businesses.

I'm now 70...I truly never thought I'd see past 40. That, and now clocking up 41 years of life with HIV, comes as a bit of a shock if I have to think about it.

It is truly a pleasure to be here in such illustrious company, though a quick reflection reminds me that there is still sorrow, that like all here present, I have seen enough death to last me several lifetimes...certainly a lot more than the average person would see in theirs, and at an age where that should not have been even a consideration.

Even having this often overwhelming sorrow for the loss of friends, acquaintances, partners, family...for rarely a day goes by when we don't think of one or another of them...this sorrow is tinged with happy memories of them, thoughts that make us smile and laugh, thoughts that keep them close, despite the ever widening distance of time.

I am thankful to be where I am now, aware that ageing itself has its challenges, especially with disabilities, and HIV always there in the background...but hey...we're here...we made it.

Survival? You bet it is...on an unprecedented scale. Not living in the past, just occasionally delving there, but living in the now!

Tim Alderman



hen you need to tell a partner, a hot hookup or injecting partner, that you've picked up a sexually transmitted infection (STI) and that they also might need to get tested, it can be an uncertain or awkward conversation to have.

What do you say? How do you tell them? How are they going to react? and can you trust them?

This process called disclosure or notification can feel difficult or even embarrassing, especially if you're unfamiliar with doing this. Whether it's a partner, lover, friend-with-benefits or fuck-buddy, this conversation can be daunting to work out the words to use or how much detail to share.

'Giving it a miss' is the easy way out. If you care about the health of your partners, this is a crucial conversation to have so they can also get tested and if possibly treated. Many partners and lovers are grateful to have been told, so they can take care of their own health, let other partners know or even be there as a support for you.

Today there's a range of options to share this news with people who need to know. Normally, telling your partners is carried out by yourself with the support of a nurse, social worker or doctor at the clinic where you were diagnosed. Of course, depending on the relationship, you might prefer to raise the topic yourself with your partner.

You can also let them know through an anonymous SMS from a website, like https://www.bettertoknow.org.au/, https://www.bettertoknow.org.au/ or https://www.thedramadownunder.info/let-them-know/.

Positive Life NSW offers another option. We have people (peers) who've been in your shoes and can support you when you're ready to notify a sex or injecting partner. We're here to support you when you're ready, whether it's an STI, hepatitis C (HCV) or even HIV.

This can be done in your own time, on your own terms, in your own way. Whether you want advice on how to work out who you need to talk with, brainstorm some ideas, or rank the order of risk among your casual or regular sex partners, reach out.

Telling partners about an STI diagnosis can be confronting. Our peers know that disclosure can be challenging, so we're going to ensure there's information tailored for 'high-risk' situations where you feel there might be physical, social or sexual violence, so your safety is the top priority. Being in control, means feeling better about yourself, and your partners are likely to respect your disclosure.

Contact Positive Life NSW if you're looking for support or if you have any questions or concerns about HIV diagnosis and disclosure on (02) 8357 8386, 1800 245 677 (freecall) or email contact@positivelife.org.au.

Providing services and community for PLHIV and their supporters in Newcastle and the Hunter Valley

Call 0411 060 154 or 4940 8393 Email admin@karumah.org.au Visit karumah.org.au



- 4 Social Club Sydney 6pm For all heterosexual people living with HIV
- 15 The Men's Room Online 6.30pm For all heterosexual men living with HIV
- 15 The Women's Room Online 6.30pm For all women living with HIV under 45 years of age
- 16 Peer2Peer Sydney 6pm For all gay and bisexual men living with HIV
- 18 Digital Mentors Sydney 12.30pm For all people living with HIV
- 24 In The Know Sydney 6pm For all people living with HIV
- 29 Positive Conversations Online 6pm For all people living with HIV
- 1 Social Club Sydney 6pm For all heterosexual people living with HIV
- 14 [+Connect] Ultimo For all people living with HIV, our partners, friends and family
- 16 More than a patient workshop Sydney 10am For all people living with HIV
- 19 Digital Mentors Sydney 12.30pm For all people living with HIV
- 19 For Women Online 6.30pm For all women living with HIV over 45 years of age
- 26 Positive Conversations Online 6pm For all people living with HIV
 - 1 World AIDS Day Event Sydney 6pm
- 4 AGM & Christmas Party Sydney 6pm For Positive Life NSW members and all people living with HIV
- 6 Combined Peer2Peer/Social Club Sydney 6.30pm For all people living with HIV





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

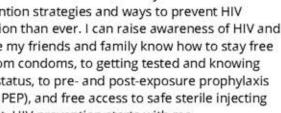
IT STARTS WITH US. ML





PREVENT I have more ways than ever to prevent HIV.

The HIV pandemic is not over. Today there are more HIV prevention strategies and ways to prevent HIV transmission than ever. I can raise awareness of HIV and make sure my friends and family know how to stay free of HIV. From condoms, to getting tested and knowing your HIV status, to pre- and post-exposure prophylaxis (PrEP and PEP), and free access to safe sterile injecting equipment, HIV prevention starts with me.





TREAT HIV medication is simple, easy and accessible in NSW.

Treatment for HIV today is extremely effective and means I can live a long healthy life like anyone else. Starting HIV medication soon after a diagnosis benefits my long-term health and wellbeing. Treatment is simple, easy and free for anyone in NSW. Taking HIV medication as prescribed means I can't pass HIV onto anyone else. Taking my medication, keeping my health appointments, self-care and taking control of my health starts with me.



HIV testing puts me in control of my health.

Anyone who is sexually active can contract a sexually transmitted infection (STI), including HIV. Getting tested for HIV puts me in control and benefits the health and wellbeing of those around me. Regular STI testing in NSW is free, anonymous, confidential, and safe for everyone. Getting tested means I can make informed decisions about my health and gives me confidence in my HIV status. I am ready to act quickly if I test positive. HIV testing starts with me.



STIGMA I can break down HIV myths and stigma.

Shame and stigma about sexual health creates assumptions about HIV. Stigma can be public, clinical, judgemental or perceived. Stigmatising comments about AIDS or HIV impacts me and my health and the wellbeing of my partners, family and friends. When I dispel HIV myths and confront HIV stigma, I lead by example. Let's shine a light on HIV stigma and discrimination, break down these barriers, and advocate for understanding and human rights. Confronting ignorance, dispelling myths and misinformation about HIV, starts with me.

- Ask 'could it be HIV?' and get a HIV test
- Normalise HIV, because it is everyone's business
- No shame in getting tested for HIV
- #NoOneLeftBehind #ItStartsWithMe
- Visit us at positivelife.org.au



The voice of all people living with HIV

ew words were added to our vocabulary, a series of acronyms that would imprint themselves forever into our memories...PCP (Pneumocystis pneumonia); KS (Kaposi sarcoma); CMV (Cytomegalovirus...one I'm intimately familiar with))... MAC (Mycobacterium avium complex); candidiasis (Thrush), toxoplasmosis, to name a few. When we asked how people were, we were really asking what did they have...and what was the prognosis! Meanwhile, the Australian nightmare was well and truly hitting home.

In 1986, my first close friend, Andrew Todd, died. At that time there was no dedicated AIDS ward, and Andrew was shifted between wards as beds were needed for other cases. On Christmas Day, we visited him in what was called St Christopher's Ward (due to patients travelling into and out of it), in Sydney's St Vincent's Emergency Department. He was very thin, and frail, but we had brought gifts for him, including sheet sets, and books. We were going to a friends place in Glebe for Christmas lunch. When the time came to leave, Andrew said to us, something that was quite upsetting for us, I have to say, that he 'wouldn't die that day, and ruin everyone's Christmas lunch'. It unintentionally did, as we waited all day on edge, for a phone call. True to his word, he didn't pass away on Christmas Day. He died on Boxing Day. It was my unpleasant duty to ring everyone at a party, and inform them. Party pooper status acknowledged!

His funeral at Eastern Suburbs Crematorium, a place we were to visit on far too many occasions, was several days later. His father had travelled from South Australia to oversee it. Myself and Sandro, both close friends of Andrew's, ended up being the middle men between those of us who wanted a funeral that was honest and respectful, and the leather community who wanted what we considered an over-the-top leather funeral. We won that one.

Towards the end of the crematorium service, as the curtains were closing over the coffin, every door in the chapel suddenly, and very loudly, slammed close. The silence after was eerie. We could say it was just the wind, but one was left wondering. Andrew got the last laugh anyway. I had lent him many novels during his hospital stays, and in his will he bequeathed them all back to me.

Sex became a conundrum. As soon as it was found that HIV was sexually transmitted, the dynamics of sex changed, at least temporarily. Some guys went celibate. Others cut out anal sex altogether. Others went to odd extremes, like standing well apart and just mutually masturbating. For a culture that was heavily geared towards sex, it was a real blow. The dynamics of 'picking up' changed significantly.

Condoms became the new order of the day, and condom and lube 'safe sex' packs were everywhere, from sex venues to pubs and nightclubs.

ACON created the Safe Sex Sluts, who at least put a bit of fun into what was now a serious subject. This, over time, created some reverse, and some dark situations. On the dark side, terms like 'bug chasing' came into being. This phrase described those who deliberately sought out HIV+ guys and indulged in unsafe sex on the purely weird chance that they would get infected. 'Breed me' could often be seen on sex sites, placed there by guys who wanted to become infected. It was strange times.

Then there were guys like me who just hated sex with condoms. They ruined spontaneity, and were just passion killers. Naturally, this meant we were seeking out guys to have unsafe sex. To this end, I restricted my sex life to sex with HIV+ guys only. It was politely referred to as 'negotiated unsafe sex'. I could never have lived with myself if I knowingly passed on HIV to another guy, but the thinking was that it was impossible to infect a guy already infected. Talk of the risk of creating a HIV mutated 'super bug' came to nothing.

Of course, this meant constantly outing yourself as HIV+, but that has never greatly concerned me, and by this time I was working on the scene so it wasn't a risky thing to do. For the record, I had a very fulfilling sex life. There was no shortage of HIV+ guys hunting for skin-on-skin sex. Another term spawned by the era of safe sex was 'barebacking'...known as normal sex (or condom-less sex) in earlier times. Yet despite all the restrictions, self imposed or otherwise, the sex-on-premises places such as Numbers Bookstore which I managed in Darlinghurst, the Toolshed, the Hellfire Club (later to become the Den Club), Club 80 (initially thought to be Ground Zero for the Sydney epidemic) and various others, and the saunas such as 253, the Roman Baths, KKK and the Steamworks, and other notorious sites such as the beat in the Green Park toilet block, and The Wall on Darlinghurst Road, thrived.

In 1984, Ward 17 South was established at St Vincent's Hospital, Sydney which became the dedicated AIDS ward. For the next 10 years it was never empty. Palliative care was through the Sacred Heart Hospice. With the support services in place, pubs and nightclubs started running events to raise money. I think if there was ever a time where I was proud to be a member of the Sydney gay community, it was seeing the huge amounts of money raised at auctions, raffles, and events. Tens of thousands of dollars were raised from the pockets of the grassroots community, and was either spread around the

various support groups, or was used to buy things like televisions for Ward 17.

In 1987, Colin Crewes, seeing the need for basic lifestyle support, such as meals, a place to meet and interact with others in the same situation, massages, hair cuts, access to magazines and newspapers, counselling services etc started the 'Maitraya Day Centre' in Surry Hills (it later morphed into the 'Positive Living Centre'). It had a constant stream of guys socialising there. At Milton's Point, NorthAIDS (Myrtle Place Centre) offered the same services to those living on Sydney's northside.

Hospitals such as Westmead, hit the headlines for all the wrong reasons; full contamination clothing for those working with HIV patients, rooms not being cleaned, meals left outside doors. According to the rumourmongers, you could get HIV from using plate/cups/cutlery/glasses/toothbrushes/towels/bed linen that any infected person had used. It was anathema despite it being washed, despite all information stating that you could not contract HIV through this means. Even the poor old mosquito copped a hiding as a means of contamination.

An advertising campaign in 1987 featuring the Grim Reaper bowling down people indiscriminately, created an apocalyptic vision of HIV that scared the life out of everyone. It was quickly withdrawn three weeks into its six week run.

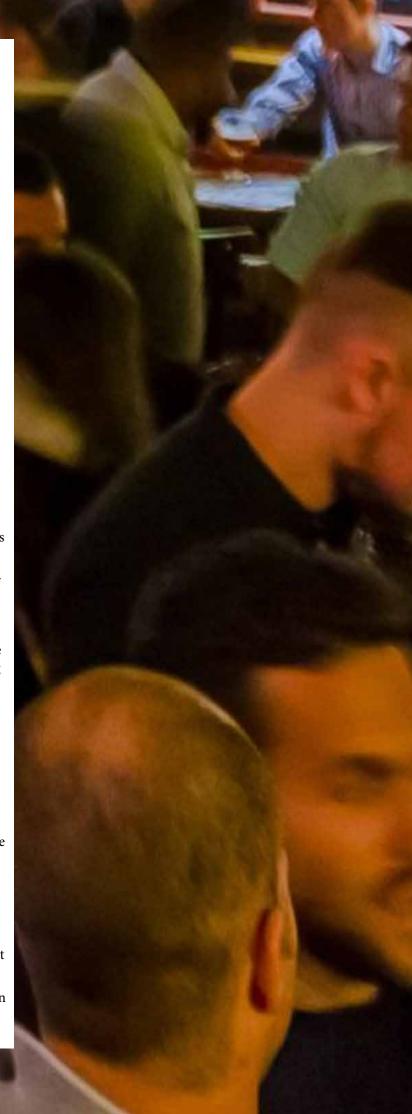
By this stage, my two years prognosis had become four years...became six...became eight. That was great for me, but not for so many others. The obituary columns in the gay rags went from scattered memoriums to pages as the death toll mounted. My life became a haze of alcohol and cigarettes, not shared alone. Our coping mechanisms were being stretched to their limit.

Funerals were a daily occurrence, as were wakes. I attended as many as I could, but I just got to a stage where I was burnt out by the continuing relentless onslaught, and stopped going.

In the 80's, I held a lot of parties with anywhere from 40-60 friends attending. By 1996, if I had tried to hold a party I would have been lucky to have dug up 10 friends to attend. In the blink of an eye, my social circle was effectively wiped off the face of the earth.

In 1997, having finally recovered from AIDS, and thinking it was time to reconnect to the community, I went out one Saturday night to The Beauchamp. For the first time in my life on the gay scene, in a crowded pub, I stood in a bar and could see NOBODY I knew. It was an incredibly lonely sensation.

- Tim Alderman



5 essential reads on breakthroughs, blind spots and new challenges

Nadine Dreyer, The Conversation

In June 1981 The US Centers for Disease Control and Prevention reported a rare form of pneumonia in young gay men in California. Although they didn't know it at the time, these were the first documented cases of AIDS.

In 1983, HIV – the virus responsible for AIDS – was isolated by virologists from the <u>Institut Pasteur</u>.

Since then <u>85.6 million people</u> have become infected with HIV and <u>40.4 million people</u> have died from AIDS-related illnesses.

In the early years the disease was known as the "gay plague" because it only seemed to affect homosexual men.

We now know that HIV is far from being a 'gay' disease.

Today women are disproportionately affected by HIV compared to men, with young women most at risk. In sub-Saharan Africa, adolescent girls and young women accounted for more than 77% of new infections among young people aged 15 to 24 years in 2022.

The 25th International AIDS Conference takes place from 22 to 26 July in Munich, Germany. It will bring together people living with HIV, scientists, policymakers, healthcare professionals and communities to share knowledge learnt from the HIV response over the past 40 years.

At The Conversation Africa, we have published many insightful articles on one of the greatest contemporary challenges in human health. Here are five of them.

Viable option

One of the most significant medical advances against HIV in the past 40 years is pre-exposure prophylaxis or PrEP drugs.

These drugs reduce the risk of contracting HIV through sexual contact, and can be taken either as an injection or as a daily pill.

A recent clinical trial in South Africa and Uganda of 5,000 young women showed a twice-yearly injection of the PrEP drug <u>lenacapavir</u> was 100% effective against infection.

Not only is this a medical milestone, as Linda-Gail Bekker explains. For young women who can't keep pills without facing stigma or violence, an injection just twice a year is the option that could keep them free of HIV.

Taunts and abuse

In South Africa unfair discrimination on the basis of sexual orientation is against the law.

But in practice many African cultures view same-sex relationships and sexual intercourse as taboo and unAfrican.

A study of men who have sex with men in the Zulu community revealed stigma rooted in cultural beliefs was rife. Participants reported ridicule and abuse, often triggering depression, suicide and drug abuse.

As a consequence of this, many were too scared to check their HIV status or seek medical care at local health clinics. As one study participant said:

I would rather die with my sickness than use such facilities.

Ikekhwa Albert Ikhile's article <u>highlights</u> the need to make healthcare more accessible for vulnerable populations.

The 'grey' epidemic

Most HIV prevention and treatment programmes and policies in South Africa remain focused on adolescents and young adults. A growing group of middle-aged and older adults with HIV, or at high risk, are being left behind.

An exception to this is the <u>Health and Aging in</u>
<u>Africa: Longitudinal Studies in South Africa study</u> –
or Haalsa as it is commonly known.

This is a decade-long project in the rural northeastern part of South Africa gaining a deeper understanding of the "greying" HIV epidemic, those people over 40 years old.

Researchers <u>found</u> that sexual activity was common among this age group: 56% of respondents had had sexual activity in the past 24 months. One in four were living with HIV and social stigma discouraged them from getting tested.

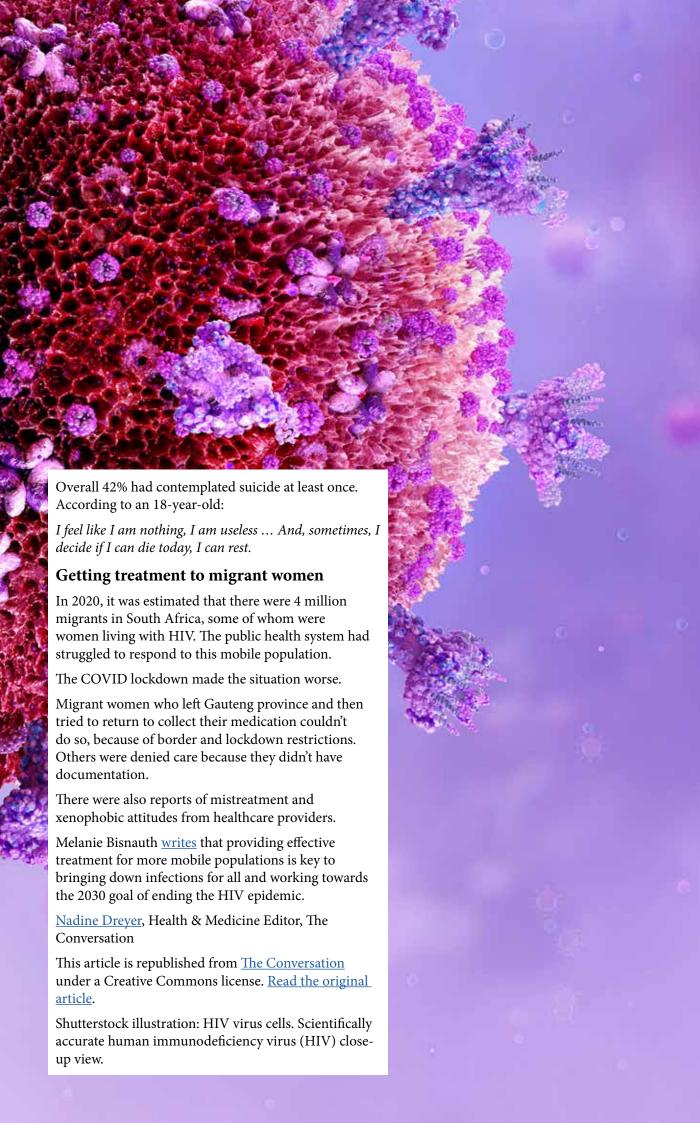
When sex is against the law

Studies elsewhere on the continent also found young people with sexual or gender diversity were at higher risk of stopping their HIV treatment, not only because of stigma but because of harsh laws.

Across 13 countries in east and southern Africa, laws and policies criminalised same-sex sexual relations.

Research in Malawi, Zimbabwe and Zambia found criminal laws and negative cultural and religious beliefs produced deeply rooted intolerance around sexual or gender diversity.

Researchers Kaymarlin Govender and Patrick Nyamaruze <u>report</u> that participants spoke about verbal harassment, gossip and physical violence.



Pe've known for some time that many people living with HIV gain weight after starting our life-saving HIV antiretroviral medication. While this has been something that people living with HIV have told us (anecdotal reports), it is only recently that clinical studies and researchers are beginning to confirm this observation although we still are not sure why some people are more susceptible to gaining weight.

Overall, the average adult living with HIV or not, will put on approximately ½ to 1 kilogram of weight each year. This small weight gain is in part due to our lifestyle factors, what we eat, when we eat, how much we eat which is different from person to person; our personal genetics, body type, how quickly we digest our food or use our energy which is also different from person to person; as well as the usual ageing process.

What we know, is that people living with HIV on antiretroviral medication gain weight faster than people without HIV. This weight gain is more common in women living with HIV, black people living with HIV, and people who have a low CD4 count and high viral load at the time of starting their HIV treatments.

Researchers are recognising that the very medication that does the best job in suppressing our viral load (integrase inhibitors also called INSTIs) with fewer side effects, is linked to this weight gain.

Dolutegravir (DTG) is a very common second-generation integrase inhibitor that's an ingredient in many of our most effective HIV antiretrovirals. HIV antiretrovirals that contain tenofovir alafenamide (TAF) have also come under scrutiny for the link with weight gain. HIV medications that include both DTG and TAF demonstrate a greater weight gain. The reasons for this are currently unknown.

To find out if your medication contains DTG or TAF or perhaps both DTG and TAF, ask your HIV prescriber next time you're renewing your prescription.

There's also little evidence to show that switching your antiretroviral medication to another one will impact this situation. Changing medication does not mean that you will automatically loose weight. The occurrence of weight or the amount of weight gain, is different from medication to medication, as well as from person to person, depending on our personal genetics, body type and individual lifestyles. What might seem to work for one person does not seem to work the same way for someone else in the same way.

So what can we do until there are new medical interventions that can affect this weight gain linked to HIV medications?

Besides the standard responses you may have already heard about lifestyle changes, diet and exercise, it can be useful to have a regular self-reflection on those things you can modify or change in your diet and daily activities.

Consider the small daily activities and movement that can have useful impacts on slowly losing any undesirable weight gain.

Can you take the stairs for one flight instead of riding the lift all the way?

Can you 'exercise snack' for 20 seconds while you're brushing your teeth, waiting for the kettle to boil or the microwave to finish?

Having an ongoing holistic discussion with your HIV doctors about your options can be an important way to stay up-to-date with any recent clinical studies, research or evidence about HIV antiretrovirals and weight gain.

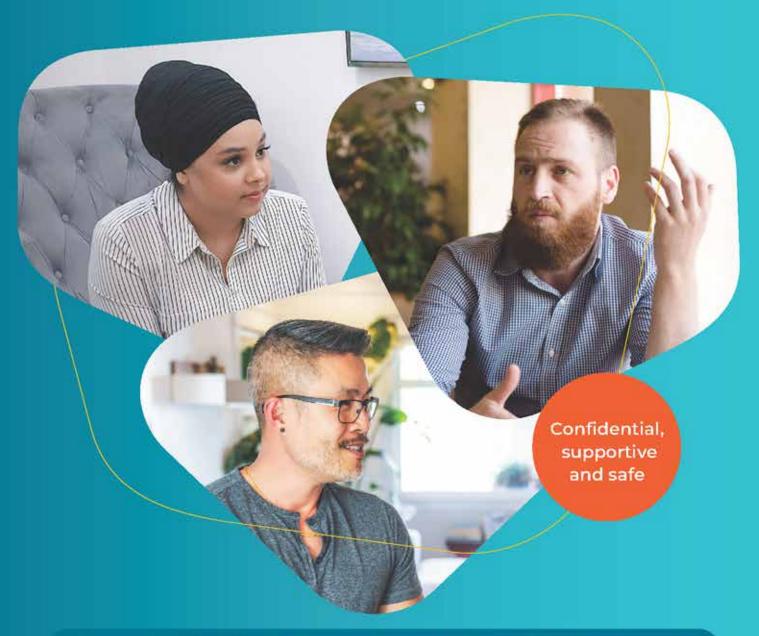
You're also welcome to get in touch with our peers also living with HIV to share your strategies and celebrate any wins you have to reduce any unwanted weight, by calling Positive Life NSW on (02) 8357 8386, 1800 245 677 (freecall) or contact@positivelife.org.au.

- Andrew Heslop



Positive Minds

Free one-to-one counselling support for all people living with HIV in NSW



Contact Positive Life NSW on (02) 8357 8386 or 1800 245 677 (freecall)

Email contact@positivelife.org.au | www.positivelife.org.au





The voice of all people living with HIV

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IIV Health Promotion

Peer Navigation + Support	Talkabout Magazine

Ageing Support	Treatments Information + Support
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Social Support	Aboriginal Health Program

Positive Life NSW works to promote a positive image of people living with and affected by HIV with the aim of eliminating prejudice, isolation, stigma and discrimination. We provide information, targeted referrals and advocate to change systems and practices that discriminate against all people living with HIV, our partners, friends, family and carers in NSW.

Phone 02 8357 8386 Freecall 1800 245 677 www.positivelife.org.au contact@positivelife.org.au