# PEOPLE LIVING WITH HIV NORTHERN TERRITORY



Don't be kept in the dark about your diagnosis!



Welcome to your magazine created by and for people living with HIV, to inform, inspire, and connect.

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#### **National HIV Organisations & Peaks**

Easily accessible just type in to search tab

#### NAPWHA (National Association of People with HIV Australia)

Regularly shares treatment updates, peer-led resources, and plain-language summaries of current research.

#### ASHM (Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine)

Leading professional body for clinicians—publishes treatment guidelines, research summaries, and training resources.

#### **HIV Futures (La Trobe University)**

Long-running national study on the health and wellbeing of people with HIV.

#### **Research & Clinical Trials**

#### **Kirby Institute - UNSW**

Australia's main centre for HIV epidemiology and clinical research; publishes annual surveillance reports and study findings.

#### **Doherty Institute – University of Melbourne**

Active in HIV cure and treatment research; updates on vaccine and cure-related trials.

#### Australian HIV Observational Database (AHOD)

Tracks long-term outcomes for people with HIV on treatment.

#### **Journals & Updates**

**HIV Australia Journal (by NAPWHA)** – accessible, community-focused updates on treatment and policy.

JAIDS and AIDS Research and Therapy – international but often publish Australian-led studies.

**Australasian HIV&AIDS Conference (annual, run by ASHM)** – best place to hear the latest treatment and prevention research.

#### <u>Plain-Language Health Resources</u>

HIV i-Base (UK-based but excellent plain-English treatment updates, widely used in Australia).

Pozhet (NSW-based) - resources for heterosexual people with HIV.

Positive Living Magazine – regular treatment and research updates in community language.

#### If you want ongoing updates:

We can become overwhelmed with the amount of information at hand.

The information provided above and news letter for subscribing are some of the best uptodate resources if you are living with HIV.

Subscribe to NAPWHA newsletters. Sign up for ASHM's HIV Listserv.

Follow Kirby Institute and Doherty Institute news pages.

Attend the Australasian HIV & AIDS Conference (lots of peer scholarships available).

#### **Health Insurance**

#### **Editorial:**

Health insurance for those living with HIV is a critically important topic, as it ensures access to essential medical care and treatments that can significantly improve quality of life. In many countries, people with HIV can obtain coverage through public or private insurance plans, although conditions vary greatly depending on the jurisdiction.

A crucial aspect is protection against discrimination: laws in many places prohibit insurance companies from denying coverage or increasing premiums based solely on HIV status. Additionally, the often high cost of antiretroviral medications can be partially covered by insurance, thus alleviating the financial burden on patients.

It is important for people with HIV to be aware of their rights and available options, always seeking expert advice to navigate the complex landscape of health insurance. Support organizations can offer resources and assistance to understand and access the benefits to which they are entitled.

Which one is right for me? There are currently more than 37 private health insurers in Australia offering thousands of different health insurance policies.

The Department of Home Affairs provides information on what you should be seeking in a private health fund here: https://immi.homeaffairs.gov.au/help-support/meeting-ourrequirements/health/adequate-health-insurance.

In deciding which fund to go for, it is important to do research and find out what fund suits your needs. There are a lot of online search engines offering a comparison search across private health policies – but be wary of these as they are often privately funded and will not always show you all the policies or offer you the best value for money.

You may also get harassing phone calls following up your query.

What about my HIV? If you are living with HIV and applying for cover, HIV is considered a preexisting condition.

The Commonwealth Ombudsman provides clear information about how private health funds must offer services to people with a pre-existing condition.

Under the Private Health Insurance Act 2007, a health insurer may impose a maximum 12-month waiting period on benefits for hospital treatment for pre-existing conditions.

Most insurers do this.

For more information go to www.napwha.org.au - FACTSHEETS

#### **National Network Organsations**



As the largest peer-led and run representative body of all people living with HIV in Australia based in NSW since 1988, Positive Life NSW is the voice of all people living with HIV in NSW. We were incorporated on 21 July 1989 as People Living With HIV/AIDS (PLWHA) NSW and changed our name to Positive Life NSW on 15 February 2008.

We work to promote a positive image of people living with and affected by HIV with the aim of eliminating prejudice, isolation, stigma and discrimination.

#### Our aims and objectives are:

To empower people living with HIV in NSW with information, referral and advice on all relevant issues; in particular health promotion information and matters dealing with life issues.

To advocate on behalf of people living with HIV and lobby government, business and non-government organisations about issues of concern to people living with HIV, with the aim of ensuring optimum well-being, care and support for people living with HIV/AIDS, our partners, family members and significant others.

To work closely with the HIV-specific and mainstream health and community sectors and other relevant organisations in the pursuit of these objectives.

www.positivelife.org.au

#### **QPP - Queensland Positive People**

Queensland Positive People (QPP), is a peer-led, community-based organisation committed to improving the lives of all people living with HIV and help reduce new transmissions of HIV and other STIs across Queensland. QPP offers the following services:

- Peer-led HIV & other STI point of care testing, prevention and education
- · Online HIV home testing kits
- Community development and peer support through social groups
- Social connection services for ageing people living with HIV
- Peer navigation to navigate the complex environment of HIV diagnosis, treatment and care
- Practical assistance with accessing medications, clinical services, food, housing and other essential support services
- Aged Care Navigation
- Alcohol and other drugs primary prevention
- Legal support and referral for stigma, discrimination, migration and the law
- Emergency funding support
- Advocacy and policy development
- Research
- World AIDS Day awareness campaign and other public health campaigns including syphilis and Mpox.

QPP are proud members of NAPWHA, QCOSS, and ASHM.

QPP is an Australian, Incorporated Association and registered <u>Australian Charity</u> for taxation purposes. We appreciate the support and assistance given by <u>Queensland Health</u>, who provide primary funding for Queensland Positive People.

www.qpp.org.au

### Doctor's Visit Checklist for People Living with HIV

Don't be shy about asking your GP about your diagnosis! particularly your diagnosis and treatment

#### **Treatment & Monitoring**

How well is my current treatment working?
What do my latest blood test results mean (viral load, CD4, kidney/liver)?
Are there any new treatments or long-acting options for me?
What should I do if I miss a dose or run out of medication?

#### **Side Effects & Interactions**

Am I likely to experience side effects from my medication?

How can I manage any side effects I'm having?

Could my HIV meds interact with other prescriptions, supplements, or recreational drugs?

#### **Overall Health**

How does HIV affect my risk for heart disease, diabetes, or other conditions? Should I be screened for cancers or other illnesses more often? What lifestyle steps (diet, exercise, sleep) can improve my health?

#### Ask About U=U & Transmission

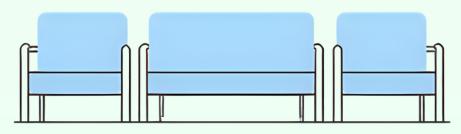
Am I currently undetectable, and what does that mean for me? How does U=U affect my sexual health and relationships? What should I tell partners about HIV transmission?

#### Mental Health & Support

Where can I get help if I feel anxious, depressed, or isolated? Are there support groups, peer programs, or community services you recommend?

#### **Future Planning**

How often should I have check-ups and blood tests? What does ageing with HIV mean for my care plan? Can I safely have children if I choose to?



www.ntahc.org.au

#### NTAHC Positive Women's Support Social Inclusion Group

My name is Busi, a member and NTAHC project officer for HIV positive women (Northern Territory) with a long-lived experience.

My diagnosis in 2002 when I was in my late thirties in the third world as married woman with 4 children did not come without challenges. Challenges were many and solutions were very few.

My mind had to navigate through a lot of things without a chronological order:

- Navigating through Widowhood
- Navigating disclosure challenges as to who to trust in the family with my positive status
- There was not treatment my life was in a limbo knowing that death was imminent
- What would happen to my children as orphans when if am deceased

During my lived experience with HIV, I have realised that positive life comes with a lot of challenges from the day you are diagnosed.

Peer groups bring a feeling of social acceptance and relief from stigma.

#### Objectives of Women's Positive Social Inclusion Group

Create a platform where women living positively can meet and share or just listen to stories with their peers without being judged.

- Each person is a custodian of their positive life stories and must choose how to tell, who to tell it and when to tell it.
- Create a connection and supportive environment from peers and have a one-to-one talk
- Get updated scientific information on medication from qualified health practitioners for our health and well being
- Get information to advocacy and support services
- Organise friendly and informal activities based on your wants and needs

Whether recently diagnosed or living with HIV for several years all are welcome to join the social inclusion group.

Join the NT Women's Support Social Inclusion Group contact Busi on 89447777 or email: busisiwe@ntahc.org.au

# Understanding HIV, its transmission, and effective prevention methods is essential for safeguarding your sexual health and well-being.

#### Living Well with HIV & Sexual Health

You deserve a healthy, fulfilling sex life.

HIV treatment = protection

- When you take treatment and reach an undetectable viral load, you cannot pass HIV on to your sexual partner.
- This is called U=U: Undetectable = Untransmitable.

#### **Protecting your partner**

- U=U means your partner is safe.
- Condoms protect against other STIs.
- Your partner may choose PrEP (a tablet that prevents HIV) for added reassurance.
- PEP is available after possible exposure.

#### **Breaking stigma**

- Many people feel shame or fear about sex after an HIV diagnosis.
- Knowing the facts—especially about U=U—can help you feel confident and safe.
- HIV does not define who you are. You have the right to love, intimacy, and a full life.

#### Remember

Always share important information with your partner -You are not a risk to your partner when you are undetectable. Knowledge is power.

Confidence is freedom.

People living with HIV can lead healthy, fulfilling lives, especially with access to effective treatment that suppresses the virus to undetectable levels. When HIV is undetectable, it is untransmitable (U=U), meaning it cannot be passed on to sexual partners.

Knowledge is truly power. Together, let's break the stigma, share the facts about HIV and U=U, and foster a community where no one is left behind.

"You know, one of the most powerful things we now understand about HIV is U=U— if your viral load is undetectable, you can't pass it on to your partner.

That knowledge can take away a lot of fear and stigma.

Some people still carry heavy feelings of shame about sex after diagnosis, but understanding that you're not a risk can help rebuild confidence and intimacy. You have every right to a safe, healthy, and loving sexual life."

#### Heterosexual Men's Advocacy Network.

Our aim is to advocate for the wellbeing of heterosexual men living with HIV in Australia and Aotearoa New Zealand.

If you are a heterosexual man living with HIV, who might be interested to connect with other straight guys LWHIV.

Please be assured them that we pay careful attention to privacy and confidentiality. Registration essential via email: <a href="https://example.com/hetman@napwha.org.au">hetman@napwha.org.au</a>

If you would need any clarification around this please feel free to call Anth on 0490 214 554 for a chat to learn more before taken the next step.

Kind regards Anth.

#### **Positive Asian Network Australia.**

#### How to join

Are you interested in joining PANA? This is open to all people living with HIV, of Asian-background, and living in Australia. You can find the registration form on the NAPWHA web site where you can fill in the form on line. Any any queries or questions to email: <a href="mailto:pana@napwha.org.au">pana@napwha.org.au</a>

#### Positive Latinx Australian Network (PLAN)

#### How to engage with us

Are you living with HIV in Australia? Do you identify with a Latin American or Hispanic background? We would like to hear from you. We meet regularly to advocate on behalf of ourselves. Our social network will aim to provide a safe inclusive spaces and ways to connect with each other for social connection.

It is also a way to exchange conversations relating to HIV and general health – this includes talking about navigating the healthcare system in Australia.

email: plan@napwha.org.au



The NAPWHA-auspiced Positive Aboriginal and Torres Strait Islander Network (PATSIN) is a national membership-based group for Indigenous people living with HIV (PLHIV).

For more information and how to engage with us https://napwha.org.au/patsin/https://napwha.org.au/wp-content/uploads/2021/06/UsMobandHIV\_2021.pdf

PATSIN works within Aboriginal Torres Strait Islander communities and service providers to represent the interests of Indigenous Australians. It exists to provide an outlet for exchanging experiences and knowledge about HIV, and to advocate for change at the community level.

PATSIN is committed to increasing education and addressing the high-level of HIV stigma within Indigenous communities.

### **LIVING POSITIVE - Northern Territory**

August 2025

## LIVING POSITIVE NT

Peer-led support and community care for Territorians living with HIV



DARWIN

# MEN'S SUPPORT SOCIAL INCLUSION GROUP



To get involved or for more information, please email Mark mark.halton@ntahc.org.au



**DARWIN** 

# WOMEN'S SUPPORT SOCIAL INCLUSION GROUP





# Researching HIV Why is it so important?

#### Why HIV research matters for people living with HIV in Australia

Below are just some of the research topics that take place each year. If you have never participated in this type of research please consider doing so - It is confidential but more importantly the long term results of these types of research have proven to benefit people living with HIV.

- · Keeps treatment up to date and monitors long-term safety and effectiveness of antiretrovirals.
- Tracks ageing and comorbidities (cancer, heart disease, mental health) so services and supports can be planned.
- Measures quality of life, stigma, mental-health and service needs so community supports and policy reflect lived experience.
- Tests and evaluates new prevention and treatment tools (e.g. long-acting injectables, new PrEP options) before
  they are rolled out widely.
- Provides the evidence base used by governments, clinics and community organisations to target resources, change eligibility rules, and reduce barriers (e.g. testing, access to PrEP and services).

#### Important current studies / focus areas (examples you may see discussed in 2024–2025)

- HIV Futures 11 (2025 activity) the ongoing round that continues to survey health, wellbeing and service needs of Australians living with HIV. the largest long running survey of people living with HIV in Australia started in 1997
- Positive Perspectives (ViiV) Wave 3 (PP3) a large global patient-experience survey (PP3 interim results 2025) that includes Australian participants; focuses on care, decision-making, U=U understanding and communication with clinicians. ViiV Healthcare+1

#### Should you consider being part of any research use trusted community channels.

- Partner with community organisations (e.g. NTAHC, Positive Life, NAPWHA, Living Positive Victoria) to share opportunities.
- · Promote through peer navigators, HIV support groups, and existing networks where PLHIV already feel safe.

#### Use peer-to-peer communication

People are more likely to engage when invited by someone with lived experience.

#### Make the purpose clear and meaningful

- Emphasise why their voice matters research directly shapes future treatments, services, and supports.
- Link the study to practical outcomes: "By participating, you help improve mental health supports," or "You're helping guide funding for better aged-care services."
- Ask for examples of how past research (e.g. HIV Futures, AHOD) has already improved care.

#### **Promote safety and confidentiality**

- Reassure participants that information is confidential, de-identified, and safe.
- Explain clearly how data is used and how privacy is protected.

#### **Diversify communication methods**

- Flyers/posters in clinics, pharmacies, and community spaces.
- Social media posts by trusted organisations.
- Short, plain-language emails or texts with direct links to surveys or trial info.
- Presentations at support groups or community forums.

#### **Reduce barriers to participation**

- Ensure surveys/studies are short and accessible (plain English, mobile-friendly).
- Provide incentives (vouchers, gift cards, travel reimbursement).
- Offer both online and face-to-face options for surveys or interviews.

#### Highlight the community benefit

- Frame involvement as giving back to the community helping shape a better future for PLHIV.
- Use phrases like:
  - "Your story matters."
  - "Together we can influence change."
  - "What you share today will help improve services tomorrow."