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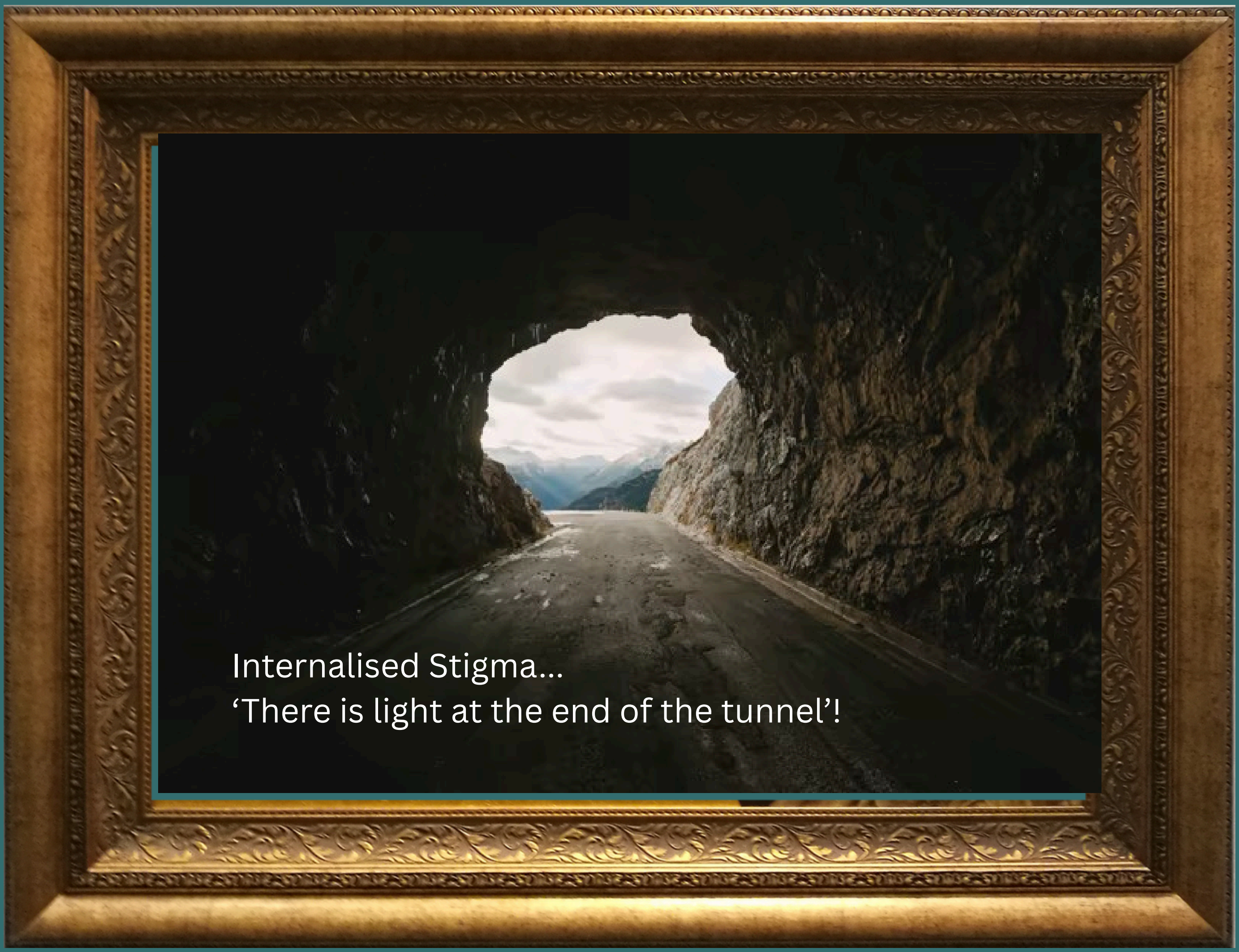
PLWHNT

PEOPLE LIVING WITH HIV NORTHERN TERRITORY



Wishing everyone the best for the coming year ahead 2026...

Produced by NTAHC's Care & Support Program with support by NTAHC Comms

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

- **Health Service Access, Especially for Older Adult.**
- Aging among people living with HIV in the NT is a growing concern.
- Access to GPs experienced in HIV care is limited, and travel costs and availability of comprehensive care can be challenging, especially outside Darwin.
- NAPWHA has been holding a regular forum for those who are aging with HIV.
- What works for you and what has been a struggle.
- Remember all of us have something to offer.
- Listening to others who have been living with HIV for some time can be empowering - You don't have to appear online if you don’t wish to - just register and your good to go.

- **NAPWHA’s BOULDER ON LINE** - Bolder Online: a beacon for older people with HIV seeking connection and support.
- In the digital age, support and community have found a new home online. The Bolder Online initiative, launched by NAPWHA, stands as a testament to this evolution.

If you would like to be included in joining this important forum, please go to the link below to register.

https://napwha.org.au/older-people-with-hiv/

The information listed in the following pages is just a guide everyone’s experience can be different. The fact that Stigma and Discrinination has continued with little change has prompted me to share the following.
By Mark Halton.
email: mark.halton@ntahc.org.au

1. Lived experience strengthens research relevance People living with HIV are experts in their own lives.

Your involvement ensures research reflects real experiences of stigma and discrimination, not assumptions made by others. This leads to findings that are grounded, accurate, and meaningful.

2. Research without lived experience risks harm.

When people living with HIV are excluded, research can unintentionally:
Reinforce stereotypes
Miss subtle or systemic forms of discrimination - Produce recommendations that are impractical or unsafe. Involvement helps prevent harm and misrepresentation.

3. Influencing policies and systems that affect daily life.

Research outcomes often inform:

- Health service delivery
- Laws and policies
- Funding priorities
-

By participating, people living with HIV help ensure these decisions reduce stigma rather than entrench it.

4. Challenging stigma through visibility and leadership

Active participation challenges the idea that people living with HIV are “subjects” of research rather than leaders and partners.
This helps shift power, normalise HIV, and reduce stigma at a societal level.

5. Improving health and wellbeing outcomes.

Stigma directly affects:

- Mental health
- Engagement in care
- Medication adherence
- Disclosure and relationships

Research shaped by lived experience is more likely to lead to interventions that actually improve quality of life.

6. Building community ownership and trust.

When people living with HIV are involved:

- Communities are more likely to trust research
- Findings are more likely to be used in real-world settings
- Outcomes are more sustainable.

This strengthens long-term change rather than one-off studies

Addressing Internalised Stigma

Addressing internalised stigma is very personal, gradual work — and it's important to be clear that there is nothing "wrong" with the individual for feeling this way. The stigma belongs to society; the work is about loosening its grip, not "fixing" oneself.

Below is a practical, compassionate framework an individual living with HIV can use.

1. **Name it — without judging yourself - The first step is recognising:**

"This feeling is internalised stigma, not truth."

Helpful practices:

- Notice self-talk that includes shame, blame, or "I'm less than"
- Gently label it: "That's stigma talking"
- Avoid fighting the thought — just acknowledge it and move on - This reduces its power over time.

2. **Separate identity from diagnosis - HIV is something you have, not something you are.**

Practical reframes:

- Replace "I am HIV-positive" with "I live with HIV"
- Write down roles and identities that existed before diagnosis — and still do.

Remind yourself: "My values, relationships, and worth did not change" - This can feel small, but language matters deeply.

3. Ground yourself in facts — repeatedly

Internalised stigma often persists despite knowing the facts, so repetition is key.

Helpful reminders:

- Effective treatment means a normal life expectancy
- Undetectable = Untransmittable (U=U)
- HIV is a manageable chronic condition - Some people keep these statements written down or on their phone for difficult moments.

4. Choose disclosure on your terms - Disclosure is not a moral obligation.

Supportive strategies:

- Decide who truly needs to know
- Practice disclosure scripts with a peer or counsellor

Start with one safe person, or none at all — both are valid. Feeling in control of disclosure often reduces shame significantly.

Addressing Internalised Stigma

5. Connect with peers — even quietly

You don't need to be "out" or highly social to benefit from peer connection.

Options include:
One-on-one peer support
Small, closed groups
Online or phone-based connections - Hearing "me too" from another person living with HIV is one of the strongest antidotes to internalised stigma.

6. Address mental health without self-blame

If stigma is affecting mood, sleep, or relationships:

- Seek a counsellor who understands HIV or trauma-informed care
- Frame support as strengthening wellbeing, not treating "weakness"

If therapy feels daunting, start with short, practical goals - Mental health care is a legitimate part of HIV care.

7. Practice self-compassion (even if it feels awkward)

Many people living with HIV are far harsher toward themselves than toward others.
Simple practices:

- Ask: "Would I say this to someone I care about?"
- Replace criticism with neutral statements
- Allow yourself good days without guilt

Self-compassion is a skill, not a personality trait.

8. Reclaim agency and meaning

For some, internalised stigma eases when they:

- Support others (formally or informally)
- Share their story safely

Advocate, educate, or simply live visibly well, This isn't required — but for many, it transforms shame into purpose.

A gentle reminder
Internalised stigma often comes in waves. Progress is not linear, and setbacks don't mean failure.
Living well with HIV includes tending to emotional health — not just viral load.

Living with HIV today is very different from even 10–20 years ago, but anxiety can still show up in very real ways.
Here are some practical, evidence-informed tips that many people living with HIV find helpful in reducing anxiety and building confidence and wellbeing.

1. Ground yourself in the reality of HIV today

Anxiety is often fuelled by outdated or incorrect information.

- HIV is a manageable chronic condition for most people on treatment.
- Effective treatment means: A normal life expectancy U=U (Undetectable = Untransmittable), including sexually.
- HIV is no longer a "death sentence" — reminding yourself of this regularly matters.

If anxiety spikes, ask yourself: "Is this fear based on today's facts or old narratives?"

2. Stick with treatment—and trust it

- Being consistent with ART does more than protect physical health.
- Routine treatment: Reduces fear of illness progression
- Builds a sense of control, Supports emotional stability.

Seeing viral load results remain undetectable can be deeply reassuring.
View your medication as self-care, not a reminder of illness.

3. Limit exposure to stigma—especially internalised stigma

Internalised stigma is one of the biggest drivers of anxiety for people living with HIV.

    - Challenge thoughts like: "I'm damaged"
    - "I'm dangerous"
    - "People won't want me"
    -

These are stigma messages — not truths.
Reframe: "I am a person living with a manageable condition. I am not my diagnosis."

4. Choose disclosure carefully (and on your terms)

You do not owe anyone your status.

- Anxiety often comes from:
    - Fear of rejection
    - Fear of gossip or judgement
- Decide:
    - Who to tell
    - When

Why It's okay to have a very small disclosure circle. Practise what you want to say beforehand confidence reduces anxiety.

5. Stay connected to other people living with HIV

Isolation amplifies anxiety.

- Peer support:
    - Normalises experiences
    - Reduces shame
    - Provides lived-experience reassurance

Hearing "me too" is powerful.
Even occasional contact (groups, online forums, peer workers) can make a big difference.

6. Look after your mental health like your physical health

Anxiety is common and not a personal failure.
Helpful strategies include:
Counselling (especially trauma-informed or HIV-aware)
Mindfulness or grounding exercises

Medication for anxiety can be helpful for some people.
Always ask your treating HIV Dr or your GP if your feeling overwhelmed.

There is often stigma related to the Mental health and wellbeing - this can happen to many people in society whether your HIV positive or Negative.

Ask for mental health support early — don't wait until you're overwhelmed.

7. Reduce "health hypervigilance"

Many people living with HIV scan their body for symptoms.

- This can increase anxiety even when nothing is wrong.

Not every headache, ache, or fatigue is HIV-related.

Ask yourself:

- "Would I worry this much if I didn't have HIV?"
- If not, pause before spiralling.

8. Build a full life beyond HIV - Anxiety shrinks when life expands.

- Invest in:
  - Relationships
  - Work or volunteering
  - Creativity
  - Physical movement
  - Purpose

HIV is part of your life — not the centre of it. Make plans that have nothing to do with HIV.

9. Be kind to yourself on hard days - Some days anxiety will still show up — and that's okay.

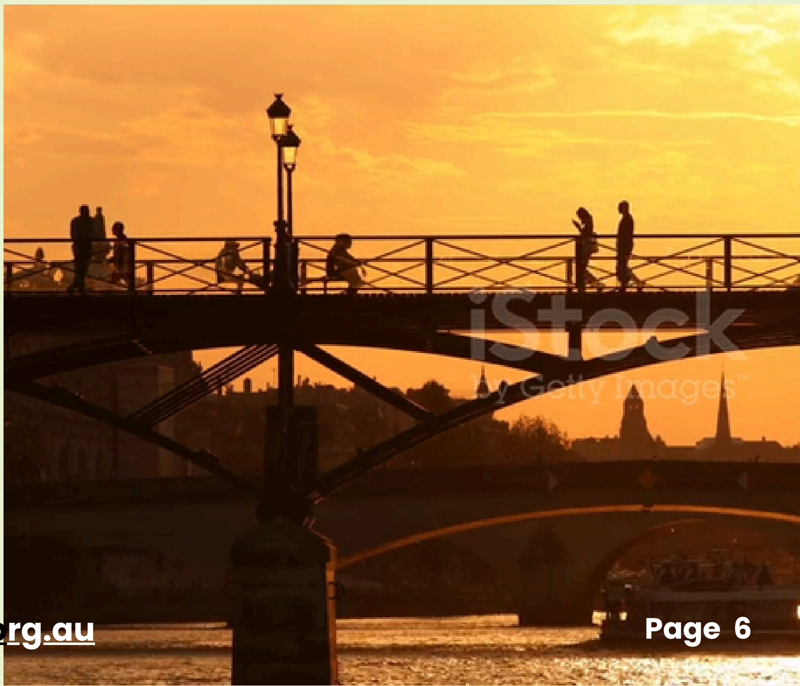
- You're allowed to:
  - Feel tired of managing HIV
  - Feel scared sometimes
  - Ask for help

Anxiety doesn't mean you're "failing".

Self-talk matters: "I'm doing the best I can with what I have."

10. Remember: you are not alone.

Millions of people are living well with HIV — including many who once felt exactly how you may feel now.



Heterosexual Men’s Advocacy Network.

Our aimisto advocateforthewellbeingofheterosexual 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: hetman@napwha.org.au

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: pana@napwha.org.au

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

PATSIN

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.

napwha
national association of
people with HIV australia

I would like to share information about NAPWHA for those who are not aware of this important organsation.

Founded in 1989, The National Association of People with HIV Australia (NAPWHA) is Australia's peak non-government organisation representing community-based groups of people living with HIV.

NAPWHA's membership of national networks and state-based organisations reflects the diverse make-up of the HIV-positive community and enables NAPWHA to confidently represent the positive voice in Australia.

Past projects

NAPWHA has a history of producing projects that are influential in the HIV sector. Many of these still hold valuable information and relevance that shouldn't be lost.

You will find a short library taking you to a few of the pages for these archived projects. While they are no longer current, they are part of NAPWHA's story.

Research

NAPWHA works to ensure the meaningful involvement of people living with HIV in a range of HIV-related research activities throughout Australia, and also internationally when Australian researchers collaborate with international research.

NAPWHA plays a key role through contributing to research advisory committees, reference groups and as representatives for people living with HIV on working groups of research studies, ensuring a voice for people with HIV in the study design and implementation.

NAPWHA's input aims to include the interests of people with HIV when working with researchers who are designing and undertaking clinical research, behavioural research, social research and cure research.

We also report and circulate important HIV research outcomes and findings to HIV positive people via social media, our newsletter, our website and through the network of NAPWHA member organisations.

For More information go to **www.napwha.org.au**

HIV Anal Cancer monitoring amoung PLWH

Why Regular Checks Are Important

Regular anal examinations can:

- Detect early signs of anal cancer or pre-cancer
- Identify HPV-related changes before they become serious
- Prevent complications by treating issues early
- Provide reassurance and peace of mind
- Support long-term quality of life

Many serious anal health conditions do not cause symptoms in the early stages, which is why regular screening matters.

How Often Should You Be Checked?

There is no single rule for everyone, but generally:

- Annual anal examinations are recommended for many people living with HIV
- More frequent checks may be advised if you:
    - Have a history of HPV, anal warts, or abnormal results
    - Experience symptoms such as bleeding or pain
    - Are over 35–40 years of age
    - Are a gay, bisexual, or other man who has sex with men
    - Have a weakened immune system

Your HIV doctor or GP can help determine what is right for you.

The ASHM Web site clearly outlines the guidleine's across the HIV Sector.

All anal cancer screening should include annual digital ano-rectal examination (DARE), examination of the peri-anal region and a thorough medical history.

The history should:

Include sexual behavioural history, as anal sexual activity may not have been previously disclosed.
Identify other potential risk activities (such as smoking) and other factors that may contribute to immunosuppression (such as certain drugs)
Identify other potential risk activities (such as smoking) and other factors that may contribute to immunosuppression (such as certain drugs)

These guidelines are intended for use by:

s100 prescribers and general practitioners who provide care to PLHIV
sexual health, infectious diseases, immunologists and HIV specialists who provide care to PLHIV.

Colorectal surgeons, general surgeons and gastroenterologists who provide anal dysplasia and cancer services clinical laboratories and pathology services trainees, registrars and surgical assistants in each of the above categories.

Specialist nursing staff who provide care to PLHIV - HIV peer navigators and peer workers, researchers and cancer organisations specialising in anal cancer and/or PLHIV health program policymakers health consumers and others with an interest in HIV and anal cancer.

For more information go to the ASHM site below.

https://ashm.org.au/resources/anal-cancer-screening-guidelines-for-plhiv

Anal Cancer Screening Guidelines for PLHIV

While uncommon in the general population, the incidence of anal squamous cell carcinoma (ASCC) is increasing, and...

ASHM Health

A **"New Normal"** is Possible: Many long-term survivors emphasize that while a diagnosis is life-changing, it is a "new beginning" rather than a punishment.

Beyond the Virus: A recurring sentiment is the phrase "I am more than a virus," emphasizing that HIV is a medical condition, not a personal identity.

The Power of Connection: Support from "HIV siblings" and peer groups is frequently cited as the most vital factor in overcoming initial fear and isolation.

Advice for the Newly Diagnosed

- **Don't Rush Your Emotions:** It is acceptable to feel shock, anger, or sadness; however, advocates urge not to stay in those feelings forever.
-
- **Knowledge is Power:** Educating oneself on modern treatments (like Antiretroviral Therapy - ART) helps replace outdated 1980s-era fears with current facts about health and longevity.
-
- **Be Your Own Advocate:** If a healthcare provider is shaming or unknowledgeable, find a new one. You have the right to respectful, expert care.
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- **Focus on Self-Care:** Living well involves daily medication adherence alongside healthy habits like good nutrition, exercise, and mental health support.

Inspirational Quotes

- *"Living with HIV has never slowed me down. I am unstoppable."* — Christabel, mother and professional.
-
- *"HIV does not make people dangerous to know, so you can shake their hands and give them a hug."* — Princess Diana.
-
- *"U=U is interrupting HIV stigma in our lives."* — Josh Robbins.
-
- *"HIV is a virus; stigma is the deadly disease."* — Queensland Positive People.
-
- *"I am a beautiful story."* — Doreen, born with HIV.

LIVING POSITIVE - Northern Territory

LIVING POSITIVE NT

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

ntahc

Alice Springs
Central Australia

Needing Support

**To get involved or for more information,
please contact Aidee**
aidee.lopez@ntahc.org.au

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

To get involved or for more information, please email Busi
Busisiwe@ntahc.org.au