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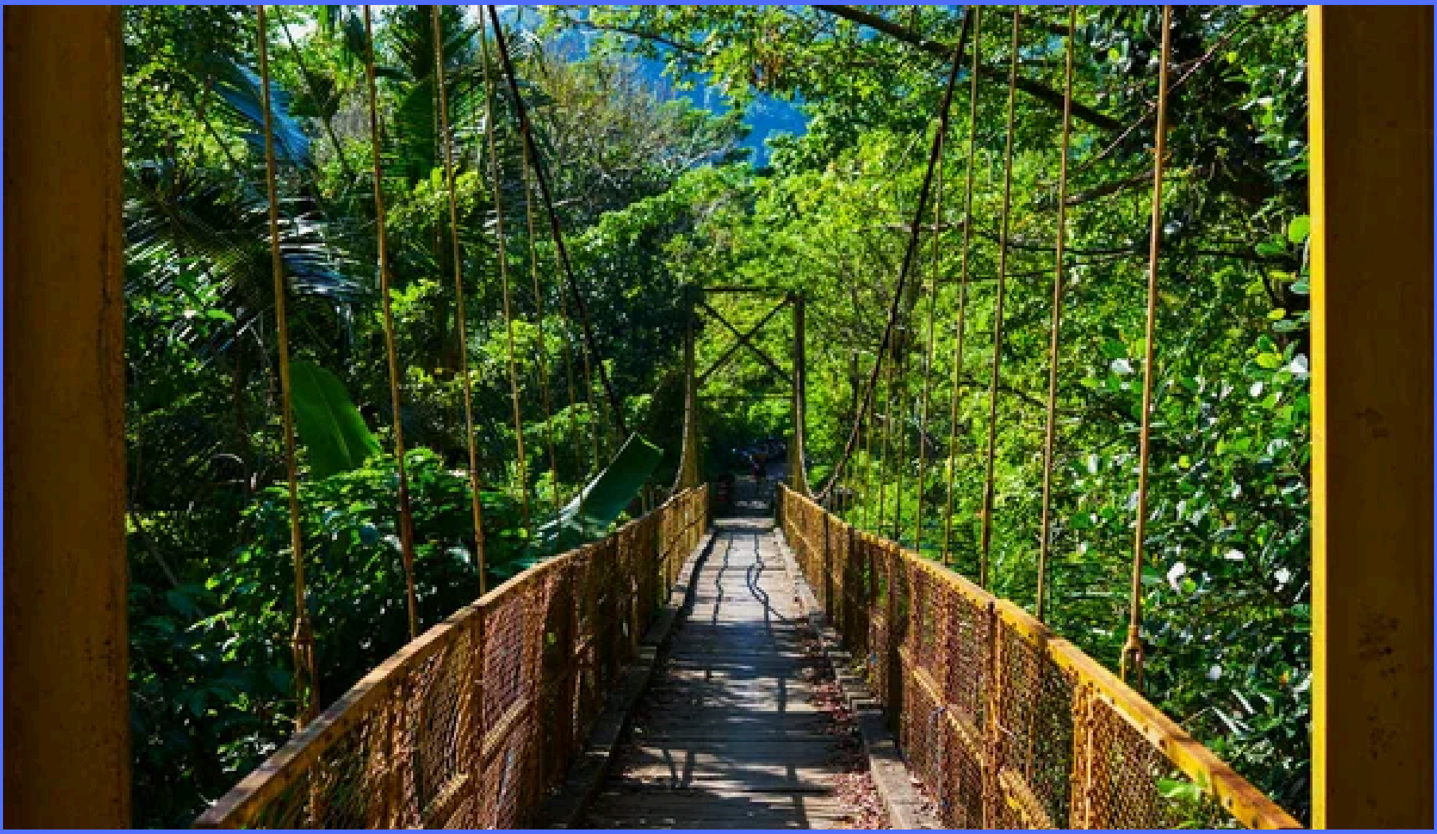
PLWHNT

PEOPLE LIVING WITH HIV NORTHERN TERRITORY



Anti retro virals and long term side effects...
What do we know?
What can we do to help Manage it.

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.

Introduction Letter – Northern Territory HIV Community Forum

Hello,
We are planning to hold a community forum for people living with HIV in the Northern Territory before the end of this financial year, and we would really value your input.
This will be a private and supportive space for people living with HIV to come together, share experiences, talk openly about the issues that matter to us, and connect with others in the community.

The forum will be open to anyone living with HIV in the Northern Territory and will be a respectful and confidential space where everyone's voice is welcome.
The aim of the forum is simple – to listen to the voices of people living with HIV and to better understand what matters most to our community right now.

Having the opportunity to hold such an event is long overdue -
Before we bring everyone together, we would like to ask:
What would you like to see discussed at this forum?

Are there topics or issues that you feel need more attention? For example, people sometimes raise things like:

- Living and ageing with HIV
- Long-term treatment and medication side effects
- Mental health and wellbeing
- Stigma and discrimination
- Social connection and peer support
- Access to services in the NT
- Housing, cost of living, or other life challenges

But most importantly, we want to hear from you about what matters most.
Your ideas will help shape the conversation and make sure the forum reflects the real experiences and priorities of people living with HIV in the Northern Territory.

A collective voice carries real strength. By coming together, we can better understand our shared experiences, highlight the challenges we face, and identify opportunities to improve care, support, and community connections. Every perspective matters, and this forum is designed to ensure that everyone's voice is respected and valued.

More details about the date, location, and how to attend will be shared soon.
In the meantime, if you have suggestions for discussion topics or would like to register your interest, please feel free to reach out.

We look forward to bringing our community together for an open and meaningful conversation.

Warm regards, Mark Halton, Case Manager - Peer Navigator - NTAHC

Living Well with HIV – But Let's Talk Honestly About Side Effects...

For more than three decades, the HIV response in Australia has been built on courage, science, community leadership and the lived experience of people living with HIV.

The introduction of modern antiretroviral therapy (ART) has transformed HIV from a life-threatening diagnosis into a manageable chronic condition. Today many of us can expect long, productive and healthy lives thanks to these medications.

But while we rightly celebrate these advances, we also need to talk honestly about something that is often left out of the conversation — the side effects of antiretroviral medications.

For many people living with HIV, treatment is lifelong. That means the medications we take every day become part of our bodies for decades.

While most modern treatments are far safer and easier to tolerate than earlier therapies, they are still powerful medications and they can affect people differently.

Weight Gain – A Shared Experience

One of the most commonly discussed issues among people living with HIV today is weight gain.

Many people taking newer medications — particularly those containing integrase inhibitors such as an example - Dolutegravir or Bictegravir — report unexpected increases in weight.

For some, the gain is modest. For others it can be significant and may increase the risk of other health conditions such as Type 2 Diabetes, cardiovascular disease, or joint issues.

Weight gain can also affect mental wellbeing. Body changes can challenge self-confidence and self-image, particularly for people who may already have complex relationships with their bodies due to illness, stigma, or ageing.

This is not about blame or lifestyle choices. Many people living with HIV maintain healthy diets and regular exercise routines yet still experience weight gain related to treatment.

If you are concerned about weight gain speak with your HIV treating Doctor or your local GP. This can often help but it does take some effort on your part.

Sleep and Fatigue

Another side effect many people speak about quietly is sleep disturbance. Some antiretroviral medications may contribute to insomnia, vivid dreams, or disrupted sleep cycles.

Lack of quality sleep can have a ripple effect on daily life — affecting energy levels, mood, concentration and overall wellbeing.

Sleep disruption can also compound other issues such as anxiety or depression, which remain important mental health considerations for many people living with HIV.

Diet, Metabolism and Long-Term Health

Antiretroviral medications can also influence metabolism and cholesterol levels. Some treatments have been linked to increases in cholesterol or triglycerides, potentially raising long-term cardiovascular risk.

This means diet and lifestyle become even more important parts of HIV care. However, it is equally important that people living with HIV receive holistic support, including access to dietitians, exercise programs and preventative health screening.

Managing HIV today is not just about viral suppression — it is about supporting whole-of-life health.

Bone Health

Some medications can affect bone density, increasing the risk of conditions such as Osteoporosis or fractures over time.

Drugs such as Tenofovir disoproxil fumarate, used widely for many years in HIV treatment, have been associated with reductions in bone mineral density in some individuals.

Regular monitoring, vitamin D levels, calcium intake, and weight-bearing exercise can help reduce these risks, but awareness is key.

Kidney and Other Organ Effects

In rare cases, some antiretroviral medications can affect kidney or liver function. While routine blood tests usually detect these issues early, they remain an important reason why regular clinical monitoring is essential for anyone on treatment.

Why Open Conversations Matter

The success of HIV treatment has rightly focused on viral suppression and the incredible reality that undetectable equals untransmittable (U=U).

But alongside this success story, we must ensure that the voices of people living with HIV remain central to discussions about treatment.

Side effects should never be dismissed or minimised. If someone is experiencing problems with their medication, there are often alternative treatment options available today.

The most important message is this: people living with HIV deserve to be active partners in their treatment decisions. If anything isnt clear about what you are being told by your Doctor, just ask them to explain it to you again.

Living Well Means Being Heard

Antiretroviral therapy has saved millions of lives and remains one of the greatest public health successes of our time. For that, we owe immense gratitude to researchers, clinicians and the activists who fought for treatment access.

But living well with HIV means more than simply surviving.

It means being able to talk openly about how treatments affect our bodies, our sleep, our mental health and our quality of life.

It means listening to community voices and continuing to improve therapies so they work not just medically, but holistically for the people taking them.
After all, treatment is not just about suppressing a virus.

It is about supporting the long-term health, dignity and wellbeing of people living with HIV.

What Are the long term side effects we should be concerned about?

Key Side Effects Highlighted in Australian HIV Guidance
Across these reports and guidelines, the most discussed current ART safety concerns in Australia include:

Metabolic effects

- Weight gain linked with integrase inhibitor drugs
- Increased cholesterol and lipid levels
- Diabetes risk.
-

Bone and kidney issues

- Reduced bone mineral density
- Kidney effects with some tenofovir formulations.

Mental health

- sleep disturbance
- mood changes.

Gastrointestinal symptoms

- nausea
- diarrhea
- abdominal discomfort.

Long-term concerns

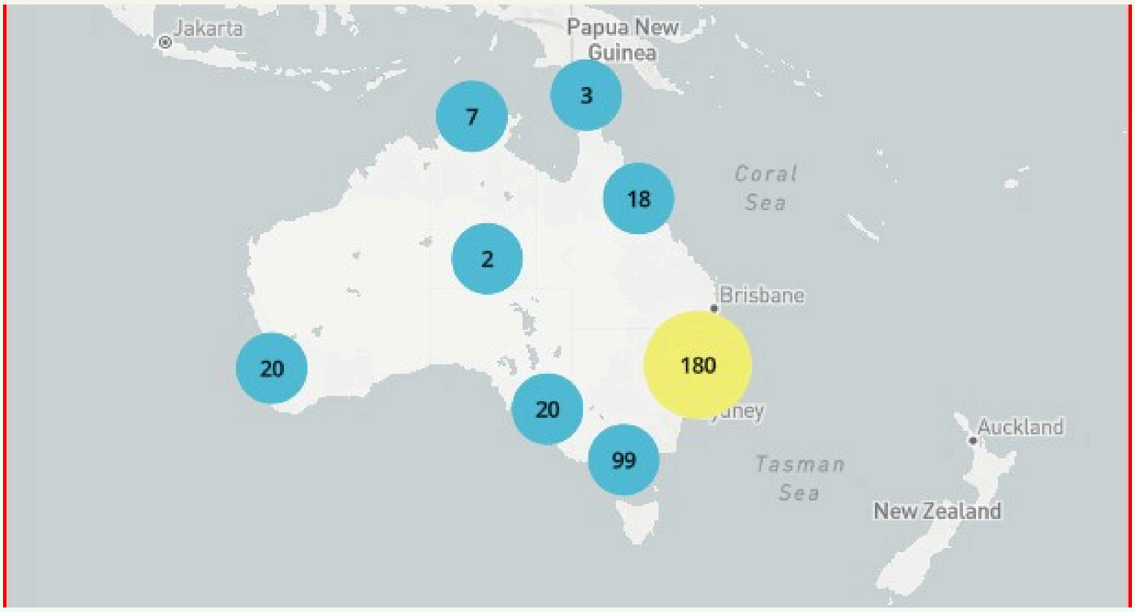
- cardiovascular disease
- ageing-related comorbidities
- drug interactions with other medications.

These are some of the more common side effects that have been indenified thorugh research and may not relate your your cercumstances or symptoms - If you are unsure about what side effects you may have alway ask your treating Doctor.

There are recomendations that could help with side effects but check with your treating HIV Doctor first.

looking for S100 prescribers around the country? follow the link below.

Sourced ASHM Web site www.ashm.org.au



Details on this map have been provided to ASHM by HIV s100 Prescribers. **Important:** This map shows prescribers who have opted to be publicly listed. Some accredited Australian HIV s100 prescribers may not appear if they have not consented to public listing.

https://ashm.org.au/prescriber-programs/find-a-prescriber/find-a-hiv-prep-prescriber/

- **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/

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.

LIVING POSITIVE - Northern Territory

LIVING POSITIVE NT

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

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
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