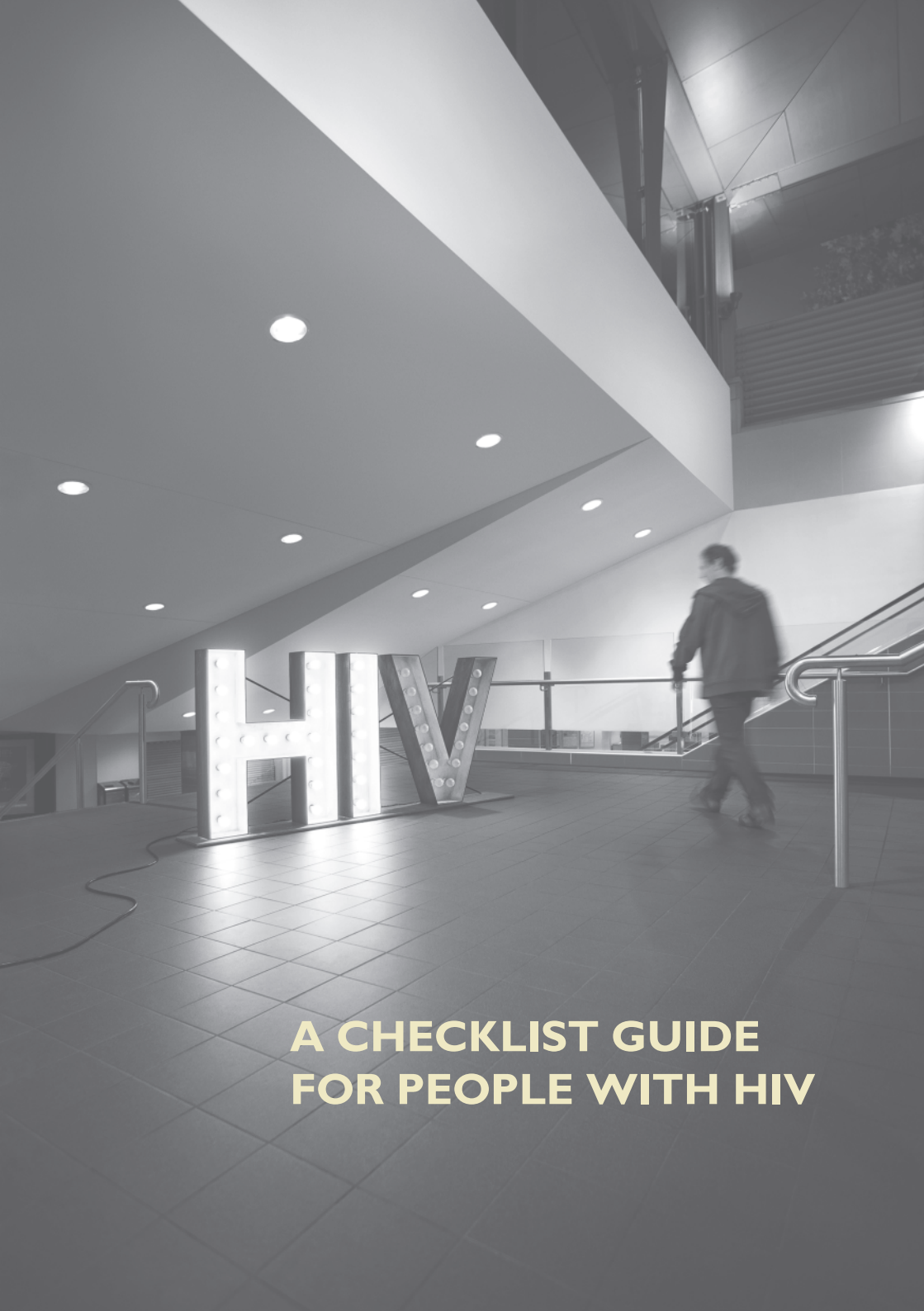


A CHECKLIST GUIDE FOR PEOPLE WITH HIV

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napwha national association of
people with HIV australia



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INTRODUCTION

LIVING WITH HIV TODAY

The picture of HIV care and treatment has changed a lot since HIV was first reported thirty years ago. Today, important scientific advances are changing the way HIV is treated and prevented.

It is important that all people with HIV know about these changes, which can help HIV positive people maintain their health and wellbeing, as well as help reduce the risk of transmitting HIV to others.

Today, we know much more about HIV and we have potent and well-tolerated treatments, with the result that many more Australians with HIV are living longer and enjoying better health. Indeed, life expectancy for HIV positive people is now approaching that of the rest of the population. **Starting treatment early is now recommended, not only for the likely health benefits, but also because being on treatment can help prevent HIV transmission to others.**

The experience of living with HIV is different for each HIV positive person. For people newly diagnosed with HIV, adjusting to being HIV positive can be a stressful time. Some people find HIV has a serious impact on their health and wellbeing. But many others maintain good health and are living full and active lives.

With better knowledge and better treatments, today's focus is on keeping people with HIV well not just over years, but decades. This requires careful planning as HIV and its treatment often complicates general health management and vice versa. Also, as people with HIV grow older, they face the same health issues associated with ageing as the general population, so these issues also need to be addressed.

Careful health care planning is the key. This Guide is to help you work in partnership with your doctor to make this happen.

HIV AND HEALTH

MAKING THE BEST CHOICES

Making decisions about health and treatment can be challenging, especially when living with a serious illness like HIV. Some people say they would rather leave the decision-making to their doctor or to others. However, NAPWHA recommends you take an active role in your health decision-making, because experience has shown that health results are better if treatment and care is planned in a partnership between patients and their doctors.

USING THIS GUIDE

NAPWHA has produced this guide to help HIV positive Australians make the best decisions they can about their health, care and treatment. The guide is based on the latest information about treating HIV.

This guide gives you a checklist of issues to work through with your doctor to help your health care and treatment planning. This will be useful for example when seeing a doctor about your HIV for the first time or when your doctor is preparing or updating your health care plan. NAPWHA recommends that all people with HIV should have a health care plan that is updated at least annually.

This guide lists the main tests and health checks that HIV-positive people should expect to receive as part of comprehensive health care. Support and information services to help with long-term living with HIV are also described.

The checklist is designed for all people with HIV. However, there are some additional issues listed for people recently infected with HIV and those with advanced HIV infection to consider.

Most of the terms in this guide are self-explanatory. However, some laboratory tests and health checks may need explaining by your doctor. There is a glossary at the end of this guide to help.

Most importantly, we hope that this guide will encourage HIV positive people to work in partnership with their doctor to produce a clear, comprehensive health care plan for living well with HIV.

WHEN TO START TAKING TREATMENT

This edition of NAPWHA's **CHECKLIST GUIDE** is based on the latest information about HIV treatment. This is an area where the science has moved quickly.

It is now increasingly clear that having untreated HIV is bad at all stages — from when someone first becomes infected with HIV through to later stages of HIV disease. However, going on HIV treatment substantially reduces ongoing immune system damage. Also, taking HIV treatment helps reduce the risk of developing health problems associated with long-term living with HIV, including the higher risk of developing cardiovascular disease, cancers, bone disorders and cognitive problems. So starting HIV treatment — as soon as you are ready — is now recommended for all people with HIV.

Another factor in favour of taking HIV treatment is the added benefit this has in reducing the risk of transmitting HIV to others, when used alongside measures like condoms and sterile injecting equipment. The role of HIV treatment in helping prevent the transmission of HIV is an important new focus in the fight against HIV in Australia and around the world.

Australia closely follows HIV treatment guidelines developed by the United States Department of Health and Human Services. The latest edition of these guidelines released in March 2013 recommends that all people with HIV should consider starting HIV treatment, whether their CD4 count is high or low or if they are newly infected or with longer term HIV.

NAPWHA considers the evidence in favour of being on HIV treatment to be compelling. However, we also reaffirm that starting treatment is an individual decision for HIV positive people and that they should decide on the basis of good information and what they consider is best for them.

A key aim of this booklet is to help you work through issues like when to start treatment with your doctor and to make decisions about your health and well-being that are right for you.

CHECKLIST GUIDE FOR PEOPLE WITH HIV

CHECKLIST OF ISSUES FOR YOU TO UNDERSTAND AND WORK THROUGH



Understand the aims of HIV care, treatment and support

For all people with HIV infection:

OVERALL AIMS

- Maintain your health and wellbeing
- Preserve and improve your immune function through HIV treatment
- Support a partnership in health care decision-making between you and your doctor

SPECIFIC AIMS

- Encourage you to know the basics of HIV and its treatment, to help decision-making with your doctor
- Check regularly for HIV-related symptoms
- Prevent or treat HIV-related opportunistic infections if your CD4 count is very low (see page 13)
- Address any other health issues you may have
- Provide information and referral to other clinical, support and information services, as needed

EXTRA POINTS to consider if you've recently tested HIV positive:

- Confirm if your HIV infection is recent or longer term, to help guide care and treatment decisions
- Start a conversation with your doctor about going on HIV treatment early
- Identify any HIV-related symptoms (e.g., HIV seroconversion illness, which can happen in people very recently infected with HIV)
- Address any other immediate health issues



Consider who should manage your HIV care and how this should be integrated into your overall health care

- Talk to your doctor(s) about the best way to manage and coordinate your HIV and general health care.
- If your usual doctor is not an expert in HIV, then co-management of your HIV infection with a doctor highly experienced in HIV is strongly recommended. This should include referral to an HIV specialist and/or regular discussions between your usual doctor and an HIV specialist.
- If you have hepatitis B or C, talk to your doctor(s) about how best to manage these infections, which can complicate HIV care.



Decide on a schedule of visits to your doctor

- Three to six-monthly visits if your CD4 T-cell count and viral load are stable and there are no health changes.
- More frequent visits may be needed if you have ongoing health problems or if you have unstable viral load or CD4 T-cell count results.
- If you've only recently been diagnosed with HIV, more frequent visits are suggested in the short term – this will also depend on arrangements about who is going to manage your HIV infection (see above).
- For people with advanced HIV infection, more frequent visits may be needed until immune function improves and any symptoms are controlled.



Develop a treatment and care plan with your doctor

- Preparing a treatment and care plan is a good way of working through your HIV and health needs. (Note: Medicare covers the preparation of care plans to support health care planning by general practitioners (GPs), specialists and other health providers.)
- Review and update your care plan regularly, as agreed with your doctor (but at least annually).
- For people with advanced HIV infection and/or ongoing health issues, more frequent updates of your treatment and care plan are recommended.



Understand **key clinical tests and health checks** and decide with your doctor **how often** they should be done

- Check on symptoms related to HIV or other causes
- Monitor for HIV-related opportunistic infections (especially for people with lower CD4 T-cell counts)
- Physical examination
- Weight and body mass index (BMI)
- Cardiovascular (heart) disease risk assessment
- Neurological symptoms/cognitive function (annually; more often if there are symptoms)
- Viral load test
- CD4 T-cell count and percentage
- Full blood count
- Blood chemistry tests (incl. fasting glucose and lipids, electrolytes, liver and kidney function)
- Urine check (for protein)
- Hepatitis A, B, C testing
- Testosterone levels (for men)
- Baseline chest x-ray
- TB (tuberculosis) test
- Pap smear (annual for women)
- Pregnancy (as relevant)
- Contraception



PHOTO: SEBASTIAN-JULIAN



Understand when to start HIV antiretroviral treatment

For people with a CD4 T-cell count of above 500:

■ Clinical guidelines recommend starting HIV treatment even if you are feeling well and especially if there are HIV related symptoms, a falling CD4 T-cell count or high viral load.

For people with a CD4 T-cell count of 500 or less:

■ Research shows that the risk of HIV-related illnesses and other problems increases further as the CD4 T-cell count falls to 500 and below.

■ Clinical guidelines strongly recommend starting HIV treatment, even if you are feeling well.

For people with HIV infection where the CD4 T-cell count is 350 or less:

■ People with a CD4 T-cell count of 350 or less are at very high risk of serious HIV-related illnesses and should start treatment without delay, even if they feel well.

EXTRA POINTS to consider:

■ More regular visits to your doctor may be needed if you are newly infected and having prolonged HIV-related symptoms (such as HIV seroconversion illness).

■ If you have HIV and hepatitis C, you may want to start HIV treatment earlier, as people who have higher CD4 T-cell counts seem to have an improved response to hepatitis C treatments.



Understand the aims of HIV treatment and the importance of treatment adherence (i.e., not missing doses)

■ The key aims of taking HIV treatment are to achieve undetectable viral load, preserve and improve immune function; and minimise any longer-term impacts of living with HIV (e.g., cardiovascular disease).

■ Taking your HIV treatment correctly is essential for treatment success.

■ Missing doses can result in drug resistance and treatment failure.

■ Learn about tips and tricks to help you take HIV treatments correctly.



If taking HIV treatments, learn about the medications, common treatment tests and HIV monitoring procedures

Just before starting HIV treatment:

- Take a HIV drug resistance test to help guide selection of drugs for your HIV treatment combination.
- Test to establish your suitability to take certain HIV treatments drugs (e.g. abacavir, maraviroc).
- Check for potential drug-drug interactions (between HIV treatments and other drugs, supplements or unconventional ["alternative"] therapies).

Soon after starting HIV treatment:

- Check if HIV treatment is working (e.g., viral load is falling; CD4 T-cells rising).
- Discuss any treatment side effects you may be experiencing and consider strategies for managing them.
- Check how well dosing suits your lifestyle (e.g., timing of doses)
- Check your adherence to treatment (i.e., whether you are taking all your prescribed doses at the right times).

Longer-term HIV treatment monitoring:

- Check if HIV treatment is working (e.g., by viral load and CD4 T-cell count tests).
- Monitor for side effects, including body shape changes; fat loss in face and other areas (lipodystrophy and lipoatrophy).
- Discuss strategies for managing any ongoing side effects you may experience.

Access to Experimental HIV Treatments:

- If your HIV treatment options are limited because of drug resistance or side effects, talk to your doctor about the possibility of obtaining experimental treatments through special access programs or clinical trials.



Review steps to prevent HIV-related opportunistic infections

- The risk of developing serious HIV-related opportunistic infections increases if your CD4 T-cell count is very low (e.g., below 200), so steps to prevent these infections from occurring or recurring should be discussed.
- Review medicines to prevent various HIV opportunistic infections, such as:
 - *Candida albicans* and other common fungal infections
 - *Pneumocystis jiroveci* pneumonia (PCP)
 - Toxoplasmosis and Cryptococcosis
 - *Mycobacterium avium* complex (MAC) (for 50 CD4 T-cells or less)
 - *Cytomegalovirus* (CMV) (for 50 CD4 T-cells or less)
- Regular physical examination, including:
 - Skin examination (for lesions, abnormalities)
 - Oral examination (for gum disease, mouth infections or other problems)
 - Eye examination (especially for those with CD4 T-cell counts below 50)



Consider **vaccinations** to prevent illnesses that can complicate HIV care

- Hepatitis A & B vaccination (Combined vaccine: two doses 6–12 months apart)
- Influenza vaccination (Annual)
- Pneumococcus vaccination (1–2 doses)
- Travel vaccinations (discuss with doctor if you are travelling overseas)



Consider steps to support good **mental health**

- Discuss your mental health and identify any issues (e.g., depression)
- Consider referral to a mental health professional, if appropriate



Consider steps to support **general health** and a **healthy lifestyle**

- Nutritional health and support – referral to dietitian if required
- Exercise programs – referral, advice and support as needed
- Lifestyle – quit smoking programs; drug and alcohol use
- Dental health check (at least annually)



Getting **more information** on HIV treatment, health, support, social wellbeing programs and prevention

Know where to get more information about:

- HIV, health and treatment (see list of references at the end of this guide)
- Support programs and services (e.g., programs for newly diagnosed with HIV; Positive Living Centres; peer support; housing support; sexuality; indigenous; women; youth; ageing)
- Support, information, counselling for partners, friends, family
- Income support, welfare benefits, financial advice and assistance services (e.g., for people who are not working)
- Life planning (life coaching)
- Living with HIV in regional, rural or remote areas

If you've recently been diagnosed with HIV:

■ Testing positive for HIV can be a stressful time. Think about your information and emotional support needs, including referral to other services and programs (there are programs for people newly diagnosed with HIV and support options for partner, friends, family).

If you have advanced HIV infection:

- If you are having periods of feeling too unwell, consider seeking support of a carer, advocate, or service organisation to help you manage and monitor your treatment and care plan and daily living support.
- Seek advice and assistance if you are considering stopping work.



Know about transmission and prevention of HIV and other STIs; sexual health; safe drug injecting

- Sexual health check (at least annually and three to six-monthly or more for more sexually active gay men), including testing for sexually transmitted infections (STIs); discussion of sexual function/libido
- Information and support on STIs and HIV transmission and prevention and safe sex practices
- Get the facts about the role of HIV treatment in helping to reduce HIV transmission to others
- Awareness of safe drug injecting practices.



Be sure you understand this checklist and how it can help you get the best health care

- If not, ask your doctor for more information. You can also get information and advice from NAPWHA, your local people living with HIV organisation or AIDS council.



WHERE TO GET MORE INFORMATION

The **National Association of People With HIV Australia (NAPWHA)** website provides useful links to information and services for people with HIV.

NAPWHA also has a clinical trial website (napwha.org.au/trials) to help keep you informed about HIV clinical research that's being done in Australia. NAPWHA encourages all people with HIV to consider taking part in clinical research – this helps advance our knowledge about HIV, which in turn leads to better treatment and care.

Your local people living with HIV organisation and AIDS council can provide you with information about living with HIV, including information about local treatment, care and support services. Contact details are on page 19.

WEBSITES

The following websites provide the latest information about HIV living and treatment and report on new developments in HIV research.

- **National Association of People With HIV Australia (NAPWHA)**
 - napwha.org.au (with links to state/territory people with HIV organisations)
 - facebook.com/napwha
- **Australian Federation of AIDS Organisations (AFAO)**
 - afao.org.au (with links to state/territory HIV organisations)
- **Ending HIV Campaign (ACON)**
 - endinghiv.org.au
 - facebook.com/endinghiv
- **Project Inform (USA)**
 - projectinform.org
 - facebook.com/ProjectInfor
- **I-base (UK)**
 - i-base.info
 - facebook.com/pages/HIV-i-Base

antiretrovirals (ARV, anti-HIV drugs, HIV treatments) Drugs that interfere with the ability of HIV to make more copies of itself (to replicate).

baseline A measurement that is used as a reference point to monitor HIV infection (such as before starting treatment or therapy, for example by measuring CD4 T-cell count or viral load).

blood chemistry tests (bloodwork) Measure a number of important chemicals produced by your body to help it function properly. Also used to assess liver and kidney function. Abnormal test results can sometimes mean that another disease is present in the body or that a specific drug is causing side effects.

body mass index (BMI) A standard guide to determine an individual's ideal body weight.

cardiovascular Concerning the heart and blood vessels.

care plan A written description of a health care arrangements, including their healthcare providers. Medicare covers the preparation of care plans to support health care planning by GPs, specialists and other health providers.

CD4 T-cell count and percentage (CD4 count, T-cell count) CD4 T-cells are a type of infection-fighting white blood cell. HIV infects and kills these cells, leading to a weakened immune system. The number of CD4 T-cell cells in a sample of blood is an indicator of the health of the immune system. A count above 500 or a percentage of 29-40% is considered normal. The CD4 T-cell percentage is the proportion of white blood cells which are CD4 cells.

clinical guidelines A document produced by experts to recommend how a particular disease should be managed, based on scientific evidence and clinical experience.

cognitive function The mental process of knowing, thinking, learning and judging.

Cryptococcosis A disease caused by a fungus which may infect lungs, central nervous system, skin, and linings of the body cavity.

Cytomegalovirus (CMV) A virus which is widespread in the community but causes no lasting illness in people with normal immune systems. People with advanced HIV may experience disease resulting from reactivated CMV infection and commonly affecting the retina of the eye, potentially leading to blindness.

drug resistance The ability of HIV to adapt so that it can multiply even in the presence of HIV treatments that would normally prevent replication. A laboratory test is used to help determine if an individual's HIV strain is resistant to any anti-HIV drugs.

electrolytes Sodium, potassium, chloride, bicarbonate, etc are important in maintaining normal regulation of cell and body functions and are used up by dehydration and kidney disease, vomiting and diarrhea.

full blood count (FBC) A test that measures the number of red cells, white cells and platelets in your blood.

glucose test A blood test that measures the amount of a type of sugar, called glucose, in your blood. High levels of glucose may indicate risk of diabetes, but other diseases and conditions can also cause elevated glucose.

hepatitis Inflammation of the liver, often caused by infection with one of a number of viruses. Untreated hepatitis can lead to liver damage and liver cancer. The different types include hepatitis A, B, and C.

immune function (immune system)

The body's defence system that protects against foreign invaders (including bacteria, fungi, and viruses including HIV) and destroys cancerous cells.

lipoatrophy A metabolic disorder in which fat in the face, arms, legs and buttocks is lost.

lipodystrophy A disturbance in the body's distribution and handling of fats sometimes resulting in fatty deposits in the abdomen, breasts and neck.

Mycobacterium avium Complex

(MAC) An infection caused by bacteria found in the soil and in dust particles. MAC is usually only found in people with CD4 counts below 50.

opportunistic infections (OIs) Illnesses caused by various organisms that are normally controlled by the immune system but which may cause ongoing disease in people with weakened immune systems, including people with HIV.

Pneumococcus Bacteria that are a common cause of pneumonia.

Pneumocystis jiroveci pneumonia

(also known as **PJP** or **PCP**) A lung infection, which can sometimes occur elsewhere in the body (skin, eye, spleen, liver or heart).

seroconversion The process by which a newly infected person develops antibodies to HIV. These antibodies are then detectable by an HIV test. Seroconversion may occur anywhere from days to weeks or months following HIV infection. A short illness with flu-like symptoms may occur during seroconversion and this is often referred to as **seroconversion illness**.

testosterone A hormone necessary for normal male sexual development and functioning and also important in maintaining muscle strength and mass.

toxoplasmosis A parasitic disease which can cause brain abscesses. Most people are infected when they are children, and the parasite lies dormant in the body until their immune system is damaged and no longer controls it.

tuberculosis (TB) A disease that usually occurs in the lungs, but may also affect the larynx, lymph nodes, brain, kidneys or bones.

urine test (for protein) Abnormal amounts of protein in the urine may indicate kidney problems.

viral load (viral load test)

Measurement of the amount of HIV virus in a sample of blood. HIV viral load indicates the extent to which HIV is reproducing in the body. HIV treatment aims to reduce the level of HIV in the blood to below the level of detection by a viral load test.

NATIONAL+STATE/TERRITORY CONTACTS

NATIONAL

■ National Association of People With HIV Australia (NAPWHA)

■ 02 8568 0300

■ napwha.org.au

■ Australasian Society for HIV Medicine (ASHM)

■ 02 8204 0700

■ ashm.org.au

■ Australian Federation of AIDS Organisations (AFAO)

■ 02 9557 9399

■ afao.org.au

AUSTRALIAN CAPITAL TERRITORY

■ People Living with HIV/AIDS (ACT)

■ 02 6257 4985

■ aidsaction.org.au/content/plwha

■ AIDS Action Council of the ACT

■ 02 6257 2855

■ aidsaction.org.au

NEW SOUTH WALES

■ Positive Life NSW

■ 02 9361 6011 Freecall 1800 245 677

TTY 131 450

■ positivelife.org.au

■ ACON (AIDS Council of NSW)

■ 02 9206 2000 Freecall 1800 063 060

TTY 02 9283 2088

■ acon.org.au

NORTHERN TERRITORY

■ People Living with HIV/AIDS (NT)

■ 08 8944 7777

■ Northern Territory AIDS and Hepatitis Council

■ Darwin 08 8944 7777

Freecall 1800 880 899

■ Alice Springs 08 8953 3172

■ ntahc.org.au

QUEENSLAND

■ Queensland Positive People (QPP)

■ 07 3013 5555 Freecall 1800 636 241

■ qpp.org.au

■ Queensland Association for Healthy Communities (QaHC)

■ 07 3017 1777 Freecall 1800 177 434

■ qahc.org.au

SOUTH AUSTRALIA

■ People Living with HIV/AIDS (SA)

■ 08 8293 3700

■ www.hivsa.org.au

■ AIDS Council of South Australia

■ 08 8334 1611 Freecall 1800 888 559

TTY 08 8362 0306

■ acsa.org.au

TASMANIA

■ Tasmanian Council on AIDS, Hepatitis & Related Diseases

■ 03 6234 1242 Freecall 1800 005 900

■ tascahrd.org.au

VICTORIA

■ People Living with HIV/AIDS (Victoria)

■ 03 9863 8733

■ plwhavictoria.org.au

■ Victorian AIDS Council/

Gay Men's Health Centre

■ 03 9865 6700 Freecall 1800 134 840

■ vicahc.asn.au

WESTERN AUSTRALIA

■ HIV/AIDS Peer Advisory Network (HAPAN) (HIV Positive Group)

■ 08 9482 0000

■ Western Australian AIDS Council

■ 08 9482 0000

■ waahc.com



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people with HIV australia