

Getting THE best HIV care

A CHECKLIST GUIDE FOR
PEOPLE WITH HIV



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NAPWA gratefully acknowledges Dr Nick Medland, who provided much of the information upon which this guide is based. Thanks also to Dr Sarah Pett, Dr Fraser Drummond, Peter Watts, Peter Canavan, Paul Kidd, Geoff Honnor and Bill Whittaker for their advice and technical review.

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May 2008

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INTRODUCTION

HIV treatment and care have changed a lot over recent years. Knowledge about HIV has increased and better treatments have been developed, allowing more Australians with HIV to live longer and enjoy better health.

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 that HIV has a serious impact on their health and wellbeing. But many others enjoy long periods of good health and live full and active lives.

With better knowledge and better treatments, today's focus is on keeping people with HIV well over the long term. However, 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 will face the same health issues associated with ageing as the general population, so these also need to be considered.

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, NAPWA recommends you take an active role in health decision making, because experience has shown that health outcomes are better if treatment and care is planned in a partnership between patients and their doctors.

HOW TO USE THIS GUIDE

NAPWA has produced this guide to help HIV-positive Australians make the best decisions they can about their health, care and treatment.

The guide gives you a checklist of issues to work through when planning your health and treatment with your doctor. The 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 of issues 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 also a glossary at the end of the guide.

NAPWA recommends that you work through this guide with your doctor – particularly when you are seeing a doctor about your HIV for the first time or when your doctor is preparing or updating your health care plan.

Through using this guide, we hope that HIV-positive people will not only be well informed about their HIV and general health but, most importantly, they will have worked in partnership with their doctor to produce a clear, comprehensive health care plan for living well with HIV.

checklist guide

FOR PEOPLE
WITH HIV

CHECKLIST OF ISSUES FOR YOU TO UNDERSTAND AND CONSIDER

Understand the **aims of HIV care, treatment and support.**

OVERALL AIMS

- Maintain your health and wellbeing.
- Preserve and improve your immune function.
- Support a partnership in health decision making between you and your doctor.

SPECIFIC AIMS

- Monitor for HIV-related symptoms.
- Address any other health issues you may have.
- Encourage you to know the basics of HIV and its treatment, to help decision-making with your doctor.
- Provide information and referral to other clinical, support and information services, as needed.

If you've recently been diagnosed with HIV:

- Confirm if your HIV infection is recent or longer term, to help guide care and treatment decisions.
- 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.**

Decide on a **schedule of visits to your doctor.**

If you have advanced HIV infection (e.g. CD4 T-cell count below 200):

- Improve your immune function and health, particularly through ARV treatment, to reduce the risk of serious HIV disease.
- Monitor for HIV-related and other health problems and treat any new ones.
- Prevent or treat HIV-related opportunistic infections (see page 13).

- Talk to your doctor(s) about how your HIV and general health care are going to be managed and coordinated.
- If your usual doctor is not an HIV expert, then co-management of your HIV infection with a doctor highly experienced in HIV is recommended. This should include referral to a doctor with high-level experience in HIV 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.

- Three to six-monthly visits if CD4 T-cell count and viral load are stable and there are no health changes.
- More frequent visits may be needed from time to time, especially to monitor ongoing problems or if you have unstable viral load or CD4 T-cell count results.
- If you've only recently been diagnosed with HIV, 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 are recommended.

Develop a **treatment & 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 GPs, specialists and other health providers).
- Review and update your care plan every three to twelve months, as agreed with your doctor.
- For people with advanced HIV infection, more frequent updates of your treatment and care plan are recommended.
- If you've only recently been diagnosed with HIV, consider a short-term care plan (for the next two to three months), until you are ready for longer term planning.

Understand **key clinical tests and health checks** – 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 & lipids, electrolytes, liver & 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)

Understand when to start
**HIV antiretroviral
(ARV) treatment.**

For people with a CD4 T-cell count of above 350:

- Evidence is growing to support starting ARV treatment earlier (above 350 CD4 T-cells), but research hasn't yet established exactly "how early is early".
- Clinical guidelines recommend that ARV treatment be considered, especially if there are HIV related symptoms, a falling CD4 T-cell count or high viral load.
- A baseline HIV drug resistance test is recommended, even if ARV treatment isn't started until later.

For people with a CD4 T-cell count of 350 or less:

- Research shows that the risk of HIV-related illnesses and other problems increases as the CD4 T-cell count falls to 350 and below.
- Clinical guidelines recommend starting ARV treatment, even if you are feeling well.

For people with advanced HIV infection (e.g. CD4 T-cell count of 200 or less):

- People with a CD4 T-cell count of 200 or less are at very high risk of serious HIV-related illnesses and should start treatment without delay, even if they feel well.

For people recently infected with HIV:

- Information is limited about the benefits and risks of ARV treatment in people recently infected with HIV (Note: it's important to understand the difference between "recently infected" and "recently diagnosed" with HIV – ask your doctor).
- Clinical guidelines are that ARV treatment should be considered optional if you've been infected with HIV within the previous six months.
- However, ARV treatment should be considered if you're having prolonged HIV-related symptoms (such as HIV seroconversion illness) or a continuing low CD4 T-cell count or high viral load.
- A baseline HIV drug resistance test is recommended, even if ARV treatment isn't started until later.

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

Additional points to consider:

- People with pronounced HIV-related symptoms or an AIDS diagnosis should start ARV treatment without delay, irrespective of how high or low their CD4 T-cell count is.
- If you have HIV and hepatitis C, you may want to start ARV treatment earlier, as people who have higher CD4 T-cell counts seem to have an improved response to hepatitis C treatments.

- The key aims of taking ARV treatment are to achieve undetectable viral load and preserve and improve immune function.
- Taking your ARV treatments 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 ARV treatments correctly.

If taking antiretroviral (ARV) treatment, understand the **ARV treatments, treatment tests and monitoring** needs.

Just before starting ARV treatment:

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

Soon after starting ARV treatment:

- Check if ARV 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 ARVs and dosing suits your lifestyle (e.g. timing of doses; food requirements for some drugs).
- Check your adherence to treatment (i.e. whether you are taking all your prescribed doses at the right times).

Longer term ARV treatment monitoring:

- Check if ARV 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 ARV Treatments:

- If your ARV 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 low (e.g. below 200), so steps to prevent these infections from occurring or recurring should be considered.
- 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 which 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 HIV+; Positive Living Centre; peer support; housing support; sexuality; indigenous; women; youth; ageing).
- Support, information, counselling for partner, 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 HIV+, and information and support options for partner, friends, family).

If you have advanced HIV infection (e.g. CD4 T-cell count below 200):

- 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 (annually; six-monthly for gay men), including testing for sexually transmitted infections (STIs); discussion of sexual function/libido.
- Information and support on STIs and HIV transmission and prevention, safe sex practices.
- Awareness of safe drug injecting practices.

Be sure you **understand this checklist** and its health implications.

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

WHERE TO GET MORE INFORMATION

The **National Association of People Living with HIV/AIDS (NAPWA)** operates a national **Treataware information line** to provide information to people with HIV about HIV treatment and care. Call **1800 817 713** from 2–7pm Monday to Friday EST.

NAPWA also has a clinical trial website (www.treataware.info) to help keep you informed about HIV clinical research that's being done in Australia. NAPWA 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. The **Treataware information line** can also assist you with questions about research.

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 at the end of this guide.

WEBSITES

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

■ **National Association of People Living with HIV/AIDS (NAPWA)**
www.napwa.org.au
(with links to state/territory people living with HIV organisations)

■ **Australian Federation of AIDS Organisations (AFAO)**
www.afao.org.au
(with links to state/territory HIV organisations)

GLOSSARY

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

antiretroviral drug resistance The ability of HIV to adapt so that it can multiply even in the presence of drugs 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.

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 & 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 around 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.

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.

lipids A general term meaning fats in the blood.

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.

neurological Refers to the central or peripheral nervous system of the body. Neurological symptoms may affect the brain or central nervous system.

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.

pap smear A test performed on a sample taken from the cervix for the early detection of cancer and other abnormalities of the female genital tract.

Pneumococcus Bacteria which are a common cause of pneumonia.

Pneumocystis jiroveci pneumonia 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 which usually occurs in the lungs, but it 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. ARV 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

■ **Treataware Information Line** **1800 817 713**

- National Association of People Living with HIV/AIDS (NAPWA)
02 8568 0300
www.napwa.org.au
- Australasian Society for HIV Medicine (ASHM)
02 8204 0700
www.ashm.org.au
- Australian Federation of AIDS Organisations (AFAO)
02 9557 9399
www.afao.org.au

AUSTRALIAN CAPITAL TERRITORY

- People Living with HIV/AIDS (ACT)
02 6257 4985
<http://aidsaction.org.au/plwha>
- AIDS Action Council of the ACT
02 6257 2855
<http://aidsaction.org.au>

NEW SOUTH WALES

- Positive Life NSW
02 9361 6011 Freecall 1800 245 677
<http://positivelife.org.au/>
- ACON (AIDS Council of NSW)
02 9206 2000 Freecall 1800 063 060
TTY 02 9283 2088
www.acon.org.au

NORTHERN TERRITORY

- People Living with HIV/AIDS (NT)
08 8941 1711
- Northern Territory AIDS and Hepatitis Council
Darwin 08 8941 1711
Freecall 1800 880 899
Alice Springs 08 8953 3172
www.ntahc.org.au

QUEENSLAND

- Queensland Positive People (QPP)
07 3013 5555 Freecall 1800 636 241
www.qpp.org.au
- Queensland Association for Healthy Communities (QaHC)
07 3017 1777 Freecall 1800 177 434
www.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
www.acsa.org.au

TASMANIA

- Tasmanian Council on AIDS, Hepatitis & Related Diseases
03 6234 1242 Freecall 1800 005 900
www.tascahrd.org.au

VICTORIA

- People Living with HIV/AIDS (Vic)
03 9865 6772
www.plwhavictoria.org.au
- Victorian AIDS Council/Gay Men's Health Centre
03 9865 6700 Freecall 1800 134 840
www.vicaids.asn.au

WESTERN AUSTRALIA

- HIV/AIDS Peer Advisory Network (HAPAN) (HIV Positive Group)
08 9482 0000
- Western Australian AIDS Council
08 9482 0000
www.waids.com

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