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HIV/AIDS and Us Mob

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GLOSSARY

AFAO

Australian Federation of AIDS Organisations

AIDS

Acquired Immune Deficiency Syndrome

Antibodies

A chemical made by the immune system to fight germs

Anti-viral treatments

A drug that works by directly attacking the virus

Bacteria

Germs that can cause infection and illness

CD4 (T4) - cell

A type of blood cell involved in protecting the body against infections

Combination therapy

Taking a combination of pills

Confidentiality

Information which is kept secret between you and your health care provider

Counsellor

A health worker who can talk with you about problems you might be having

HIV

Human Immunodeficiency Virus

Immune System

Your bodies protection against illness (like a shield)

Immunodeficiency

Your body is not able to build up a normal protective response

Hep B

Hepatitis B – a type of hepatitis virus which is mainly spread by sex

Hep C

Hepatitis C – a type of hepatitis virus that is mainly spread by sharing injecting equipment

Monitoring

Regularly having tests with your doctor or sexual health care worker

NACCHO

National Aboriginal Community Controlled Health Organisations

NAPWA

National Association of People Living with HIV/AIDS

NSP

Needle and Syringe Program - a place where people who inject drugs can get equipment, information and support

PLWHA

People Living With HIV/AIDS

STIs

Sexually Transmitted Infections

Treatments

Medicines used to remedy or fight a disease

Viral load

The amount of HIV virus present in blood

Virus

A small organism (germ) often causing diseases (illness)

Window period

The length of time after infection with HIV that it takes to develop antibodies that can be detected in an HIV test

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Front cover artwork

Title: "Dialogue"

Artist: Arone Raymond Meeks
Resides: Cairns, Qld



This work represents communication between people on a verbal level and how they feel and respond to each other.

The figures are linked by their hands and crosshatching. Crosshatching is a symbol for fertility and the earth.

The background depicts elements of the tropics, such as the reef, rainforest and coral spawning.

The kidney shapes within the figures represent the emptiness we may feel when responding to confronting situations.

This resource is intended for a broad audience of Aboriginal and Torres Strait Islander Peoples. AFAO recognises that this resource may not represent all aspects of the diversity within these Indigenous communities and cultures.

Our aim is to increase awareness of HIV/AIDS, treatments, and care and support issues.

Any element of the text of this resource can be changed or adapted to better suit the needs of Aboriginal and Torres Strait Islander communities.

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Who is this book for?

This booklet is for Aboriginal and Torres Strait Islander people.

This book contains information that deals with both men's and women's business.

It may also refer to deceased persons.

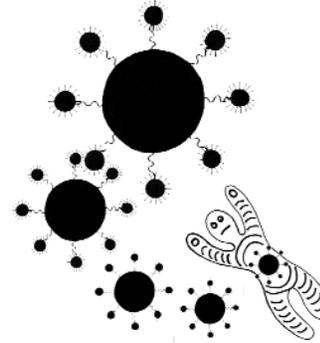
You may want to read it because:

-  ***You want to get tested for HIV***
-  ***You have been tested and know you have HIV***
-  ***You have family or friends who have HIV***

HIV/AIDS in our community affects us all.

What is HIV?

HIV is a small germ (called a virus).



HIV can get into your body if you:

Have sex without condoms



Share needles/syringes



Get someone else's blood into cuts



Having HIV can make it harder for your body to keep itself well. You may get sickness that your body could normally fix. Unlike most other germs (viruses, bacteria, fungi) HIV stays in your body.

**HIV stands for
Human Immunodeficiency
Virus**

Immunodeficiency means that your immune system isn't working properly. Your immune system is what your body uses to stay well when it is working properly. It fights off germs (called viruses, bacteria or fungi) so they can't make you sick.

What happens when HIV gets into your body?

At first not much happens and most people with HIV stay well for some years.



Then slowly the HIV hurts the immune system so it can't protect you from germs very well.



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Then people start to get sick in different ways.



If you've had HIV for a long time without any medicines, it can start to make you feel sick. You might:

-  Feel tired with loss of energy
-  Get sweats at night time
-  Lose weight

These symptoms can be caused by lots of things. The only way to know if it is HIV is to have a test.

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Some other HIV health problems that can happen

There are some health issues that happen more often when you have HIV.

Some of these are:

-  Skin problems, like itchy and dry skin and skin sores
-  Trouble with teeth and gums
-  Difficulty sleeping

It is a good idea for people with HIV to see their health worker or doctor as often as possible.

There are some other sicknesses that can cause more serious problems for people with HIV.

They include:

Hepatitis-liver sickness, which can make HIV harder to treat.

Diabetes-sugar sickness, can be made more likely by some of the medicines used for HIV.

Tuberculosis or TB is most often a lung infection that stays in your body and can cause illness when HIV damages your immune system.

Sexually Transmitted Infections (STIs) that can make it easier to get and pass on HIV.

What is AIDS?

When people have had HIV in their bodies for some years and their immune system is damaged, some will get unusual illnesses.

They are said to have **AIDS**.



**AIDS stands for
Acquired Immune Deficiency
Syndrome**

Acquired means you can get HIV from someone else who is already infected (by sex without condoms or sharing needles/syringes).

Immune Deficiency means your immune system isn't working well to protect you from disease.

Syndrome means you could get sick in different ways from different germs. Not everyone with AIDS is sick in the same way.

Some of the main sicknesses when you have AIDS

If your immune system gets damaged, your body can get some very serious germs and sickness. They can be:

Pneumocystis Carinii Pneumonia (PCP) - a germ that hurts your lungs.

Mycobacterium Avium Complex (MAC) - a germ that damages your main organs.

Tuberculosis - a serious lung infection.

Toxoplasmosis (Toxo) - an infection mostly of the brain, but it can also hurt other parts of the body.

Cryptosporidiosis (Crypto) - which is bad diarrhoea (runs).

Cytomegalovirus (CMV) - an infection usually in the eye.

Candidiasis (Thrush) - a germ (fungal infection) that usually happens in the mouth, throat or vagina (women's private parts).

Kaposi's Sarcoma (KS) - are purplish coloured raised spots on the skin.

How is HIV passed on?

Both men and women can get HIV. HIV is passed on through blood, semen (cum), vaginal fluids, or breast milk from another person.

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HIV can be passed on:

By anal or vaginal sex without condoms (called unsafe or unprotected sex).



By sharing needles and syringes.



By sharing razors and other cutting, piercing or tattooing equipment.

By getting HIV infected blood, semen (cum), vaginal fluids or breast milk on broken skin (cuts) or around your eyes or inside your nose and mouth.

From mother to baby, either before the baby is born, during the birth or through breast feeding.



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Women with HIV can talk to their doctor or health worker about how to have healthy babies who won't get HIV.

Looking after your skin is important. Cuts on the skin and sores like mouth ulcers, swollen gums, weeping eyes, scabies and sexually transmitted infections (STIs) can increase the risk of HIV transmission.

HIV is not passed on by:

Kissing or hugging

Sharing cups or forks

Toilet seats or towels

Mosquitoes



How can I make sure I don't get HIV or pass HIV on to others?

If you are going to have anal or vaginal sex with someone, using a condom is the safest way not to get HIV or pass it on.

You can make sure you don't get HIV or don't pass it on by:

Always using condoms for sex



Never sharing anything with blood in it like needles, syringes, razor blades or tattooing and piercing equipment.



Never getting someone else's blood into a cut.



If you have to clean up blood, wear gloves (or plastic bags if you don't have any gloves).



Cover up cuts.



Ceremonial practices, body piercing and tattooing must be done with clean knives, razor blades and needles. Anything with blood on it must not be shared.

Having HIV doesn't mean you can't do Law (Men's/Women's Business), you just need to find out how to be safe. If you are worried about HIV and Law, you should talk to your health worker or Elders in your community.

How do I know if I have HIV?

You may not know you have HIV if you have not become sick or had a blood test. Once infected, it may be a few years before your immune system is damaged and causes health problems.

There is a simple blood test that can tell you if you have HIV. Ask your doctor, nurse or Aboriginal Health Worker about it.

The test is called an ***HIV antibody test***. HIV antibodies are signs of HIV found in your blood.

If you have recently been infected with HIV you might experience what is called ***seroconversion illness***, which can feel like having the flu. Not everyone gets this illness or knows that it is happening.

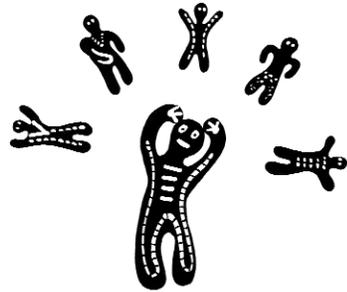
If you think you might have been infected with HIV and are experiencing ***seroconversion illness***, you should talk to your doctor or health worker.

If your test result is ***negative***, this may mean that you do not have HIV. If you have been sharing needles or having sex without a condom since your test, then you will need to have another test three months later to be sure.

A negative test result doesn't mean that you will never get HIV. Don't share injecting equipment. Always use condoms for sex.

It's your business

Getting tested for HIV is your own private business.



Only your doctor, nurse or Aboriginal Health Worker needs to know. They are not allowed to tell anyone else unless you say they can.

Before you get tested you should think carefully about who you want to tell. It can be good to tell someone you trust, so they can give you support, but you don't have to tell everyone.

When you have an HIV blood test:

-  You have the right to yarn with a counsellor before and after the test.
-  Your results are private business.
-  Blood samples have codes not names on them.
-  Only your doctor or health care worker can tell you your results.

Other illnesses

Having sex without condoms can also give you other STIs (sexually transmitted infections), which can be easily treated with medicine, but cause serious problems if you don't get treatment. If you have an STI, this can make it easier to get or pass on HIV.

If you have been having sex without condoms, it would be a good idea to get tested for other STIs at the same time.

Sharing needles and syringes can also give you other BBV (blood borne viruses) like hepatitis B or C. If you have been sharing needles and syringes, it would be a good idea to get tested for other germs at the same time.

What can I do if I have HIV?

If you have just found out that you are HIV positive, there are a few things you will need to do or think about.



-  Getting support from family, friends or health services.
-  Choosing a doctor or HIV specialist that is right for you.
-  HIV medicines (treatments).

Having HIV is serious, but not the end of the world. There are some medicines (treatments) you can take to control HIV.

If you are HIV positive (you have HIV) it is important to keep checking your health to see how much HIV you have in your blood and how much it has hurt your immune system. Every three to six months, you should go to your doctor for two blood tests: the **viral load test** and the **CD4 cell count**. This is called **health monitoring**.

The viral load test shows how much HIV is in your blood. If the viral load is high, there is a greater chance you might get sick.

CD4 cells (sometimes called T4 cells) are an important part of your immune system. They protect you by finding germs and sick body cells and killing them. HIV attacks these CD4 cells, so they can't protect you from diseases anymore.

The CD4 cell count test shows how strong or weak your immune system is. If the CD4 cell count is low, you might be more likely to get sick.

These tests help you and your doctor to know when you should start taking anti-viral treatments.

If your viral load is low and your CD4 count is high - You do not need to take treatments.

If your viral load is high or your CD4 count is low - Your doctor may suggest that you start taking medicines (treatments).

Anti-viral treatments are medicines that slow HIV down and keep your immune system strong. This is good, but these treatments also make some people feel unwell (called side effects), so it is better to not take them until you need them.

You will also need to monitor your health in other ways, like looking after your teeth, eyes, chest, bones, cholesterol and liver. Your doctor or health care worker will need to help you do this.

If you would like to read more about monitoring your health, there is a small book available from your AIDS Council called ***Taking Care of Yourself.***

HIV positive women who are pregnant should start taking anti-viral medicines early. This will help keep the baby safe from HIV.

Taking medicines (treatments)

There are different kinds of HIV medicines (also called treatments).



The main ones are called ***anti-viral medicines (treatments)***. They do not get rid of HIV from your body, but they can slow it down and keep your immune system strong.

Most anti-viral medicines are tablets or capsules. Most people with HIV take more than one kind at a time. This is called ***combination therapy***. It is important to take them exactly the way the doctor tells you or they may not work.

Your doctor will talk to you about which anti-viral medicines might be best for you. All anti-viral medicines have some side effects. This means they make some people feel unwell. You may get headaches, feel tired, get dizzy, feel like vomiting or have diarrhoea (runs).

You may need to try a few different medicines to find ones that don't make you feel too bad. Everyone is different. Sometimes **complementary therapies** and eating the right food can help stop the side effects.

Taking a break from your medicines

After a long time taking anti-viral medicines, some people with HIV want to take a break to stop the side effects.

You will need to plan how to stop taking medicines safely. Otherwise you can get **drug-resistant virus**, which means your anti-viral medicines won't work anymore.

If you want to stop taking your medicines, it is very important to talk to your doctor first.

You will also need more health monitoring (viral load and CD4 count tests) to check that you are staying well while you take the break, because some people get very sick very fast. It is not safe to take a break on your own.

Side effects of the medicines used to treat HIV

The medicines used to treat HIV can slow down the damage that HIV does to your body - but like all medicines they have side effects.

The main ones are:

-  ***Diarrhoea*** - the runs
-  ***Lipodystrophy*** and ***Lipoatrophy***
- these change what happens to fat on your body
-  ***High cholesterol*** - which can increase the chances of a heart attack
-  ***Osteopenia*** - problems with your bones

These side effects are more common if you've been on medicines for a long time.

It is important to tell your doctor or health worker if you have these side effects so they can try to stop them becoming too serious.

Complementary therapies

There are other kinds of therapy that can help to keep you healthy and feeling well, but they do not stop HIV. They are known as complementary therapies and they can help with HIV treatment side effects and feeling sad.

Some examples of complementary therapies are:

-  ***Traditional bush medicines***
-  ***Herbal, naturopathic and homeopathic medicines***
-  ***Nutritionist*** (advice about food)
-  ***Massage and reflexology*** (foot massage)

 **Acupuncture** (needles)

 **Aromatherapy** (scented oils, often used with massage)

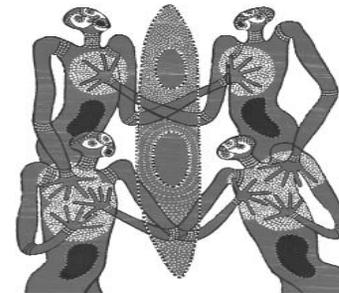
 **Meditation** (deep resting)

You can find out more about complementary therapies by asking your AIDS Council, PLWH/A group, Positive Living Centre or Aboriginal Health Worker. The lists at the back of this booklet tell you how to find them.

Healthy tucker, rest and exercise, like playing sport or walking, will help to keep you well.

Care and support

You are not alone. People with HIV need care and support, but it's up to you who you tell.



Different people living in different communities may need different kinds of care and support.

Care and support from family and friends is usually the best you can have. If you are HIV positive and have not told your family, friends or partner, then this is something you might need to think about. They may be able to help you through any worries that you have, help you to eat the right foods and to take your treatments exactly the way the doctor tells you.

Care and support can come from many people and places, like your doctor, nurse or Aboriginal Health Worker. If you have worries or feel sad, it can be good to have a yarn with these people or a counsellor.

Positive Living Centres have counselling and some complementary therapies for free. They can be a good place to get together with other people with HIV to share tips on living with HIV, treatments or just have a yarn.

It is important to find out where you can get care and support. Your AIDS Council or Aboriginal Health Worker can tell you what care and support services there are near you. You can find their telephone number and address in the back of this booklet.

Some AIDS Councils and health services have 1800 numbers. You can call this number for free to talk to someone about any questions you have.

What can I do if someone I know has HIV?

You can help by:

 **Finding** out about HIV so you can stay safe and also help them.

 **Telling** other people in your community how to stay safe so they don't worry about getting HIV.

 **Asking** the person with HIV how they would like your help.

 **Helping** them to eat the right foods and take their medicines when and how the doctor tells them.

 **Being** there, hugging them and showing that you care.

 **Respecting** other people's business. Only tell others if you have permission.

It is important not to listen to rumours or gossip - be careful and think how you would like people to be if you were HIV positive.

Care and support yarns

Neville Lives in Sydney

I am an urban Aboriginal man who is HIV (+). For most of that time I have been out on the gay scene, mostly in the larger cities. I have been able to access a range of HIV/AIDS services from health care to housing.

I remember in the early days, I was always looking after other brothers and even a lover that needed care and support from me. I had my partner with me when I got the results of my HIV test. It was not a matter of me having to tell him but more about comforting him and answering his questions.

At first, I had so many things rushing around in my head. I felt that I had to tell so many people, my family, friends, workmates and acquaintances. This was just an immediate reaction to my results. I then realised that I did not have to tell everyone straight away

and it was up to me. I could choose to tell people when I knew a bit more about what it all meant to me.

Telling someone your HIV status is completely up to you and you should not feel that you have to tell anyone if you don't want to.

Support can come in all forms, but for me it is simply my family, friends, accessible health services, access to medications and ability to make my own decisions about treatments and HIV. Most of all, for me it is the fact that people have an understanding.

For me care and support are the two major areas that I need to make sure are available in my life, so that I can live a normal day-to-day existence.

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Jo ***Lives in the Northern Territory***

I found out I was HIV positive around six years ago. I told Mum first and then the rest of the mob. It was a bit hard at first cause they didn't understand and I really had to explain what it all meant.

This was when I really needed care and support, not only care for me but support from health services to help me explain things to my mob.

After about six months I moved into town. I needed to get out of the community to move on with my life. I've been going backwards and forwards just to see Mum and the kids and when I go home I know everyone is cool with my HIV.

What I really needed was the support from other positive mob, someone to talk with when you're down or having problems with the treatments or just confused.

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My friends and family are the best care and support for me. It wasn't easy at first. I had to tell them about my health but I'm glad I did 'cause I couldn't cope without them.

How to contact services that can help you

This section tells you about the types of services that are available and how to contact those in your State or Territory.



1800 telephone numbers are free if you are calling from outside the city.



This mark means that a service has Aboriginal and Torres Strait Islander staff.

AIDS Councils

Every State and Territory has an AIDS Council and some have offices in regional towns. Some are big and offer many information and support services. All can tell you more about HIV and AIDS and tell you the best places for you to get the help you need.

PLWH/A organisations and Positive Living Centres

PLWH/A stands for People Living with HIV and AIDS. There are PLWH/A organisations in all States and Territories. They provide a safe place for people with HIV to get together, as well as confidential (private) support, advice and referral to services.

In some states, PLWH/A organisations are based in Positive Living Centres, where many support services like free/cheap meals, vitamin supplements, counselling and complementary therapies are available for people with HIV.

Needle and Syringe Program (NSPs) Exchanges

If you inject drugs you can get new gear and helpful information from Needle and Syringe Programs (NSPs). You can ask the AIDS Council or your health worker where to find one near you. NSPs also give support and advice about HIV, hepatitis and ways to look after yourself.

Make sure you return your used needles and syringes or throw them away safely inside something hard, like a plastic bottle with a lid, so other people don't get hurt by them.

Aboriginal Community Controlled Health Services

Aboriginal Medical Services can provide confidential testing for HIV and other STIs (sexually transmitted infections), which are diseases you can get from sex without a condom, as well as general health care, counselling and support. Some can provide HIV treatments.

Other health services

You can choose which service you use. If you don't like one or worry that they can't keep secrets, then you can try another one.

Many other health services like hospitals, community health centres and some private GPs (doctors) can also do HIV antibody testing and other STIs testing, as well as provide HIV treatments, health monitoring and support.

New South Wales

AIDS Council of NSW (ACON)

9 Commonwealth St
Surry Hills NSW 2010
02 9206 2000 or 1800 063 060
www.acon.org.au

ACON Indigenous workers

02 9206 2113 or 02 9206 2042

ACON Western Sydney office

02 9204 2400

ACON Mid-North Coast office (Port Macquarie) 02 6584 0943

ACON Northern Rivers office (Lismore) 02 6622 1555

ACON Hunter office

(Newcastle) 02 4927 6808

ACON Illawarra office

(Wollongong) 02 4226 1163

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People Living with HIV/AIDS NSW

Room 5, level 1
94 Oxford St
Darlinghurst NSW 2010
02 9361 6011
1800 245 677
www.plwha.org.au

Positive Living Centre

703 Bourke St
Surry Hills NSW 2010
02 9699 8756

Queensland

Queensland AIDS Council (QuAC)

187 Melbourne St
Sth Brisbane QLD 4101
07 3017 1777
1800 177 434 (outside Brisbane only)
Statewide Men's Healthline
1800 155 141
www.quac.org.au

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 **QuAC Indigenous workers**
07 3017 1737

QuAC Cairns office
07 4041 5451

Cairns Indigenous Project
 269-277 Hartley St
Portsmith QLD 4870
07 4035 6491

QuAC Gold Coast office
07 5575 8739

QuAC Sunshine Coast office
07 5452 9805

QuAC Townsville office
07 4729 2263

Sexual Health Information Line
1800 177 434

Queensland Positive People (QPP)
Statewide Office
289 Vulture St
Sth Brisbane QLD 4101
07 3013 5555

QPP Brisbane: 07 3846 3939
QPP Gold Coast: 07 5576 8366
QPP Sunshine Coast: 07 5441 1222
OPP Rockhampton: 07 4938 7720
QPP Mackay: 07 4953 5071
QPP Townsville: 07 4775 4803
QPP Cairns: 07 4051 1028

Northern Territory

**Northern Territory AIDS & Hepatitis
Council (NTAHC)**
 46 Woods St
Darwin NT 0801
08 8941 1711 or 1800 880 899
www.ntac.org.au

NTAHC Alice Springs Office
14 Railway Terrace
Alice Springs NT 0870
08 8953 3172

People Living with HIV/AIDS NT

C/- NT AIDS Council
46 Woods St
Darwin NT 0801
08 8941 1711

Western Australia



West Australian AIDS Council (WAAC)

664 Murray St
West Perth WA 6872
08 9482 0000
www.waaids.com

South Australia

AIDS Council of SA (ACSA)

64 Fullarton Rd
Norwood SA 5067
08 8334 1611
www.acsa.org.au

People Living with HIV/AIDS SA

16 Malawa St
Glandore SA 5037
08 8293 3700
www.hivsa.org.au

Victoria

Victorian AIDS Council – Gay Men’s Health Centre (VAC/GMHC)

6 Claremont St
South Yarra VIC 3141
03 9865 6700
www.vicaids.asn.au

People Living with HIV/AIDS VIC

6 Claremont St
South Yarra VIC 3141
03 9865 6772
www.plwhavictoria.org.au

Australian Capital Territory

AIDS Action Council of the ACT (AACACT)

16 Gordon St
Acton ACT 2601
02 6257 2855
www.aidsaction.org.au

People Living with HIV/AIDS ACT

16 Gordon St
Acton ACT 2601
02 6257 4985
www.aidsaction.org.au

Tasmania

Tasmanian Council on AIDS, Hepatitis & Related Diseases (TasCAHRD)

319 Liverpool St
Hobart TAS 7000
03 6234 1242

www.tascahrd.org.au

National Organisations

Australian Federation of AIDS Organisations (AFAO)

PO Box 51
Newtown NSW 2042
02 9557 9399

www.afao.org.au

National Association of People Living with HIV/AIDS (NAPWA)

PO Box 51
Newtown NSW 2042
02 9557 8825

www.napwa.org.au

Australian Injecting & Illicit Drug Users League (AIVL)

GPO Box 1552
Canberra ACT 2600
02 6279 1600

www.aivl.org.au

Aboriginal Community Controlled Health Services

Aboriginal Community Controlled Health Services (ACCHS) can provide testing for HIV antibodies and other STIs (sexually transmitted infections), which are diseases you can get from sex without a condom. They also provide general health care, counselling and support. Some can also provide assistance with HIV treatments.

The following State and Territory organisations can tell you where your nearest ACCHS is located.

**Victorian Aboriginal Community
Controlled Health Organisation (VACCHO)**
03 9419 3350

**Aboriginal Health & Medical Research
Council of NSW (AH&MRC)**
02 9698 1099

**Queensland Aboriginal & Islander Health
Forum (QAIHF)**
07 3393 0011

**Aboriginal Health Council of South
Australia (AHCSA)**
08 8431 4800

**Western Australia Aboriginal Community
Controlled Health Organisation
(WAACCHO)**
08 9202 1393

**Tasmanian Aboriginal Health Services
(TAHS)**
03 6231 3527

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**Aboriginal Medical Services Alliance
Northern Territory (AMSANT)**
08 8981 8433

Other useful booklets

Protecting our future
An information guide on HIV/AIDS, STIs & hepatitis C for Indigenous communities.

Holding our own
An information guide on HIV/AIDS, STIs & hepatitis C for Indigenous Gay Men and Sistersgirls.

HIV Tests and Treatments
Information and advice to help you make decisions.

Taking care of yourself
A guide for people with HIV/AIDS.

HIV+ Gay Sex
A booklet about being gay, having HIV and sex.

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At home, away

A pocket guide for gay men who are planning to travel.

Interactions and dangerous liaisons

Information about interactions between anti-HIV and recreational (party) drugs.

You may be ready to party, but your drugs still have to work

Useful information if you're considering taking a temporary break from HIV drugs because you're planning to party.

Treat yourself right

Information for women with HIV/AIDS.

The states you're in

A booklet for gay men in country and regional Australia about health and safety at home and away.

This and other useful information is available at your local AIDS Council.

