

TOP TIPS

For Living Well
with HIV



A Plain English Guide

Introduction

There are challenges for people with HIV, but HIV is not a death sentence. You can work and have a career. You can have a normal and long life with medicines for HIV.

It is important for you to know the current information to manage HIV. Sometimes, this can be a lot of information for you.

The tips in this book were collected from people with HIV, people who teach about HIV, and HIV doctors. These people have chosen these tips as the most important for you to know.

The tips are not in any order and this is not everything you need to know. It is a guide to give you important information so you can ask your doctor or other people questions if you need to.

The 'Contacts' pages at the back of this book give you the names, websites and phone numbers of places that can help you with more information on the tips, including multicultural organisations, AIDS councils and People Living with HIV (PLHIV) organisations. Some multicultural organisations can also give you information in your own language if you need it.

Interpreting services are also listed at the back of this book. You can have an interpreter with you when you are talking with doctors or other services. Ask for an interpreter if they do not offer one. Telephone interpreters are also available anywhere in Australia. A telephone link will be provided between you, your service provider and an interpreter. This is called TIS.

It is against the law for doctors, health services, interpreters, or other organisations to give any information about you to anyone else, unless you say they can or in very special circumstances. If this happens, there are Health Service Complaints Commissions and legal assistance organisations listed in the back of this book that can help you.

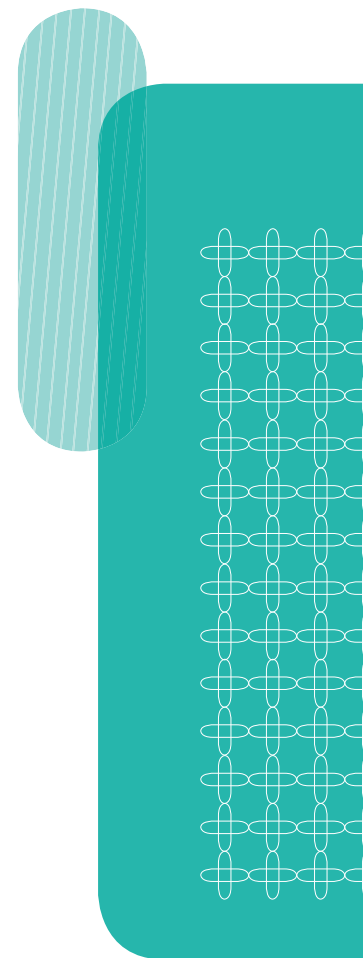
01

Doctor

It is important to have a good relationship with your doctor. Get a doctor who is easy to talk to, explains things clearly and has managed HIV before. Some doctors might also speak different languages. You can get advice about finding a doctor from your AIDS council or People Living With HIV (PLHIV) organisation.

Doctors are not allowed to give information about you to anyone else, unless you say they can or in very special circumstances.

If you are not happy with the health care you get, you can complain. The 'Contacts' pages at the back of this book has a list of the Health Service Complaints Commissions in each state.



02

Stop Smoking

If you smoke, stopping is the best way to improve your health.

Smokers who are HIV positive are more likely to get heart disease, different kinds of cancer and other infections. Men who smoke are also more likely to have erection problems.

Speak to your doctor or AIDS council or People Living With HIV (PLHIV) organisation for more information.

You can also speak to your doctor about things that can help you stop smoking. There are also places that provide information and services to help you stop smoking at the back of this book.



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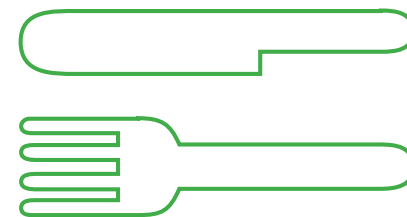
Diet & Exercise

People with HIV can get early heart disease and other diseases such as diabetes. To help stop these, it is important to have a healthy weight by eating well and doing regular exercise.

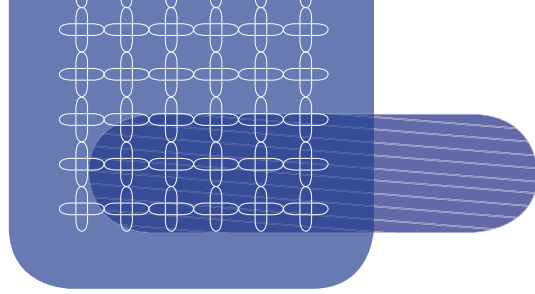
A general multivitamin may be helpful if you are not having a well-balanced diet, but it cannot replace eating well.

You can also reduce some of the side effects of HIV medicines with the types of food that you eat and when you eat them.

Speak to your doctor or a HIV dietitian for more information.



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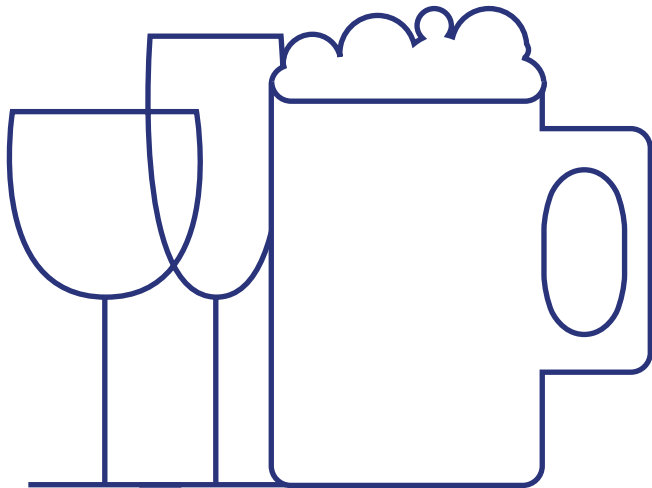


Alcohol

Drinking a lot of alcohol can cause problems for you if you are taking HIV medicines, and make it harder to take your medicines properly.

It can also make side effects of HIV medicines worse, and slow down your recovery from other infections.

Alcohol use can be linked with taking more risks in sex. Know your limits and protect yourself and your partners from HIV and other infections.



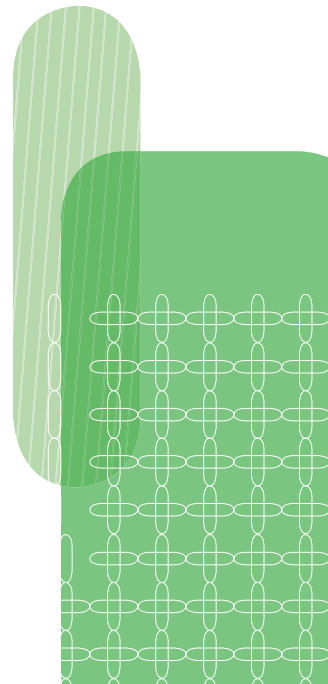
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Party Drugs

Ecstasy, Crystal (Ice) and other party drugs can harm you now and later. Using Crystal (Ice) can damage your brain.

Some party drugs can make HIV medicines not work as well or have worse side effects. Party drugs can mix badly with some HIV medicines. This can cause dangerous problems, even death. Using party drugs, staying up for long times and not eating enough can make it harder for your body to fight infections.

If you are on HIV medicines and use party drugs, you could try not taking both at the same time and wait at least a couple of hours between them. Taking party drugs can be linked with taking more risks in sex. Know your limits and protect yourself and your partners from HIV and other infections.



06

Other Medicines & Therapies

Medicines prescribed to you by a doctor, medicines given to you by a chemist, and other medicines and therapies given to you by other services can all mix with HIV medicines.

This can change how well the HIV medicines and the other drugs and therapies can work. This includes the contraceptive pill and implants for women. Some HIV medicines make the pill less effective if women are taking it to stop getting pregnant.

Talk to your doctor before starting any other medicines and therapies.



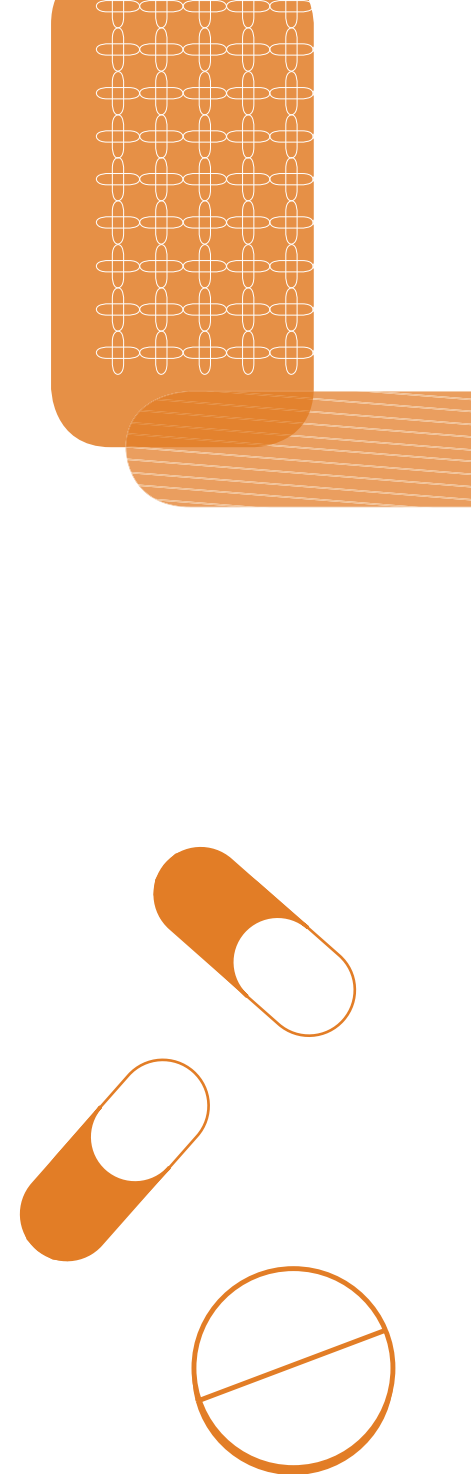
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Starting HIV Medicines

If you haven't started taking HIV medicines yet, speak to your doctor about when to start. Doctors are talking to their patients about starting earlier than they used to. If you have had HIV for a long time, your doctor may suggest starting HIV medicines straight away.

There is a book called 'HIV Tests and Treatments'. It has information on the HIV medicines that are now available. It also has information on some common tests that can help you decide about starting HIV medicines. You can get it from your AIDS council or People Living With HIV (PLHIV) organisation or the AFAO website (listed at the back of this book).

Any decision about HIV medicines needs to be discussed fully with your doctor.



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HIV Medicines & Side Effects

Side effects are the most common problem with HIV medicines. Talk to your doctor about ways to help make side effects better.

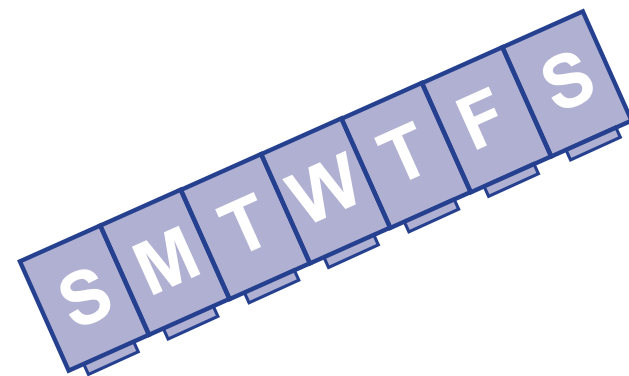
There are booklets called 'Managing Side Effects' and 'HIV Tests and Treatments' that you could find helpful. You can get them from your AIDS council or People Living With HIV (PLHIV) organisation or the AFAO website (listed at the back of this book). Any decision about HIV medicines needs to be discussed fully with your doctor.

Talk to your doctor about new medicines you could get. Even if your current medicines are working, there could also be new medicines that could work. These new medicines could be easier to take, have less pills every day and have less side effects.



09

Taking HIV Medicines



Always take your HIV medicines exactly as your doctor tells you to. Your HIV medicines might not work if you don't. This can mean that your medicines and other similar medicines can stop working to fight your HIV. This will make your HIV harder to treat.

Talk to your doctor first before you stop taking your HIV medicines. Some medicines have to be stopped in special ways. You have more of a chance to get an infection or an AIDS-defining illness if you take a medicines break. You could consider changing to different drugs instead. Any decision about HIV medicines needs to be discussed fully with your doctor.

For more information about why taking your HIV medicines properly is important, speak to your doctor or contact your AIDS council or People Living With HIV (PLHIV) organisation.

10

Checking Your Health

See your doctor every 3 months to do blood tests to check your viral load (the amount of HIV in your blood) and CD4 count (how well your body can fight infections). This is also very important if you have had HIV for a long time. Your doctor will also do other tests to check for side effects and damage to your organs. These tests may help you make decisions about HIV medicines. Any decision about your HIV medicines needs to be discussed fully with your doctor.

The book called 'HIV Tests and Treatments' could be helpful. You can get it from your AIDS council or People Living With HIV (PLHIV) organisation or the AFAO website (listed at the back of this book).

This is also a good time to talk to your doctor about other areas of your health, as well as about how you are feeling.



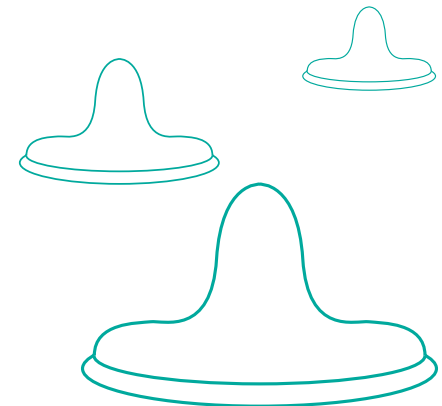
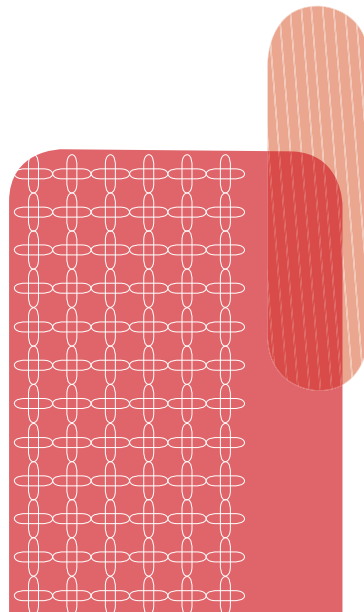
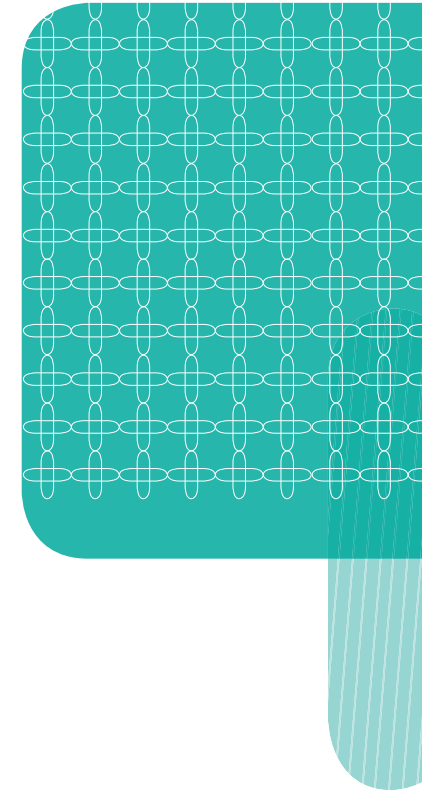
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Safe Sex

Use condoms and water-based lubricant to avoid passing on HIV when you have sex. This will also give you and your partners some protection from most other sexually transmissible infections (STIs). Ask your doctor for tests for STIs when you get your blood tests done every 3 months.

There is a very low risk of passing on HIV with oral sex, but using a condom or dental dams (square pieces of thin rubber) will also protect you and your partners from other STIs.

You can buy condoms and lubricant from supermarkets and chemists. You can also buy condoms from vending machines in some public bathrooms. You can get condoms and lubricant, and dental dams from sexual health clinics for free. You can also ask at your AIDS council. Condoms come in different shapes, sizes, thicknesses, flavours, textures and colours. Try different ones and find one that suits you or your partner.



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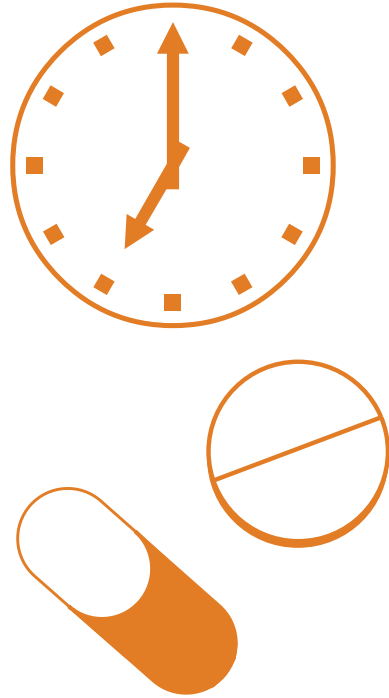
PEP

Accidents can happen.

If the condom broke or if you think you have put another person at risk of getting HIV, there are medicines to help stop them from getting HIV. The medicines are called PEP (post-exposure prophylaxis). They are the same medicines that people with HIV take.

They must start PEP in less than 72 hours after they were put at risk, but it is best in less than a few hours.

To find out where they can get PEP or for more information, call your nearest major hospital, call your AIDS council, or go to www.getpep.info



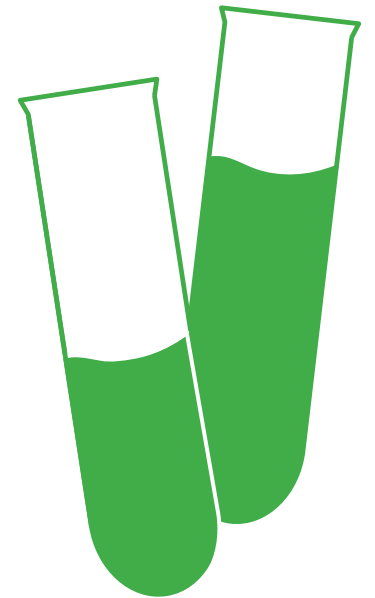
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Viral Load

Your viral load is how much HIV is in your blood. HIV is still in your body if the blood tests show an undetectable viral load. It just means that the tests can't measure the small amounts of HIV in your blood.

You can have an undetectable viral load in your blood, but have more HIV in other body fluids such as semen, vaginal fluids and the fluid lining of the rectum and anus. This would increase the chance of passing on HIV to your partners.

Research says an undetectable blood viral load in your blood makes the risk of passing on HIV smaller. But it has not been proven to stop the risk. If you had an undetectable viral load result at your last blood test, you should still have safe sex by using condoms and water-based lubricant.



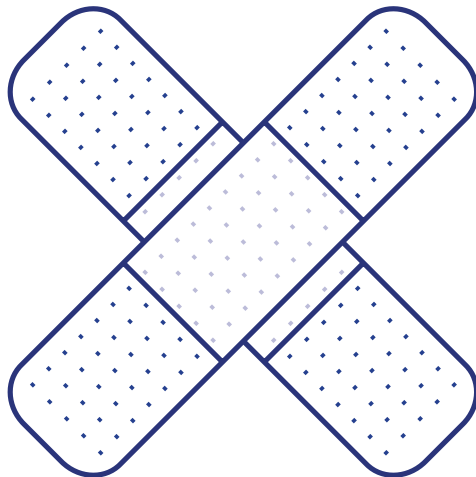
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Other Infections

If you have another infection when you are HIV positive, it can make the other infection more serious. It can also make it harder for your body to fight HIV and other infections.

If you have a sexually transmissible infection (STI), such as syphilis and chlamydia, as well as HIV, both the STI and HIV can be easier to pass on to your partners. Some STIs can increase the amount of HIV in your body. It can also make it harder for your body to fight infections. Get regular STI tests. You can get tested for STIs when you go to your doctor for your other tests to check your health. Many STIs do not show signs.

If you and your partner are HIV positive and do not use condoms, it is possible to get a different kind of HIV. Getting a different kind of HIV (called reinfection or superinfection) can reduce the types of HIV medicines you can take.



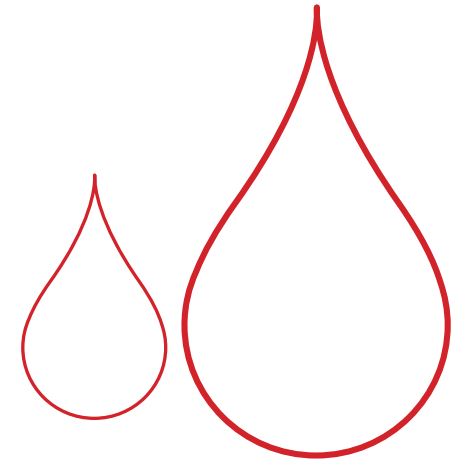
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Hepatitis C

Hepatitis C is mainly passed on through sharing drug injecting equipment. It can also be passed on through sex without a condom and particularly sex that involves blood.

Having HIV and Hepatitis C can be serious. It can make both HIV and Hepatitis C develop faster in the body. It can also make both harder to treat.

If you are injecting drugs, do not share any needles or equipment, including spoons and tourniquets. During sex, wash hands and toys and change condoms and gloves between partners.



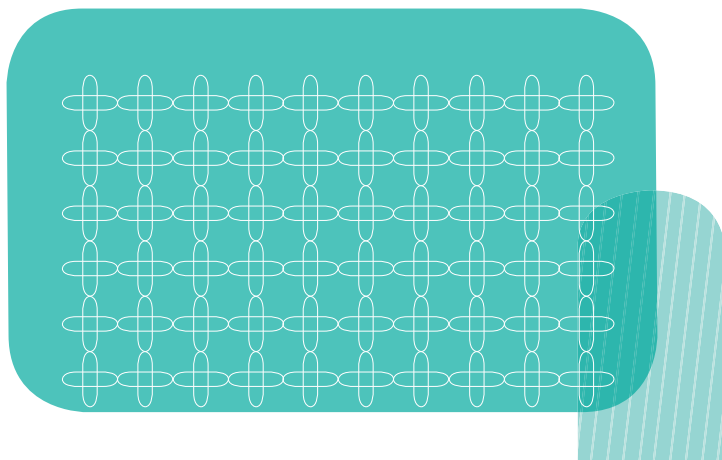
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STI Testing & Treatment

If you have sex, ask your doctor for tests for sexually transmissible infections (STIs) when you get your blood tests done every 3 months. This includes blood and urine tests as well as throat, vaginal and anal swabs. STI tests don't happen unless you or your doctor ask for them.

Many STIs do not have symptoms, so it is important to have regular STI tests.

Some STIs, such as syphilis, are serious and hard to treat if you have HIV.

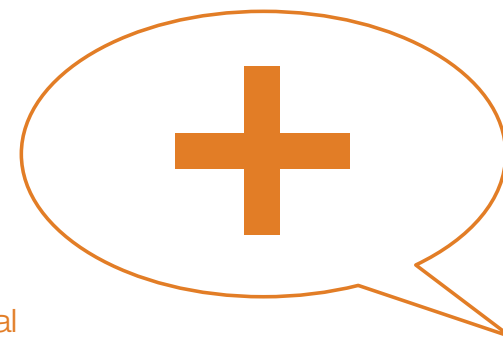


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Telling People

You do not have to tell your friends, family, boss or the people you work with you are HIV positive. It can be hard to choose who you want to tell, and it might be hard to talk about it in your community. Many people worry that they will be rejected when they tell people. Think about who will give you support, and who will keep it private.

You do not have to tell every doctor, dentist or other health service that you are HIV positive, but it is a good idea to tell them so they can make the right decision for your health. These health services are not allowed to give information about you to anyone else, unless you say they can or in very special circumstances.



Telling your partners can be hard. A counsellor can help when and if you decide to tell your partners. In some states, the law requires you to tell any sexual partners. Each state has different laws so ask your local Legal Aid Centre or AIDS council. You can also talk to places such as the HIV/AIDS Legal Centre (HALC) and your AIDS council or People Living With HIV (PLHIV) organisation.

18

Vaccinations

There are vaccinations available for several other infections. Talk to your doctor about getting vaccinated against Hepatitis A, Hepatitis B, Pneumonia and Flu (yearly vaccine).

These infections can make it harder for your body to fight HIV and can change how well you can take your HIV medicines. These infections can develop faster in the body for people with HIV.

Ask your doctor if other vaccinations might be an option for you, such as for the human papilloma virus (HPV), the virus that causes warts (this may not work as well if you have had HPV before).

Also talk to your doctor about vaccinations you should not get. If you are going overseas, talk to your doctor about the vaccinations you can have and give yourself enough time to get them.

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Cancer

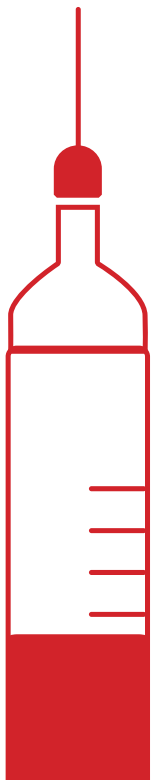
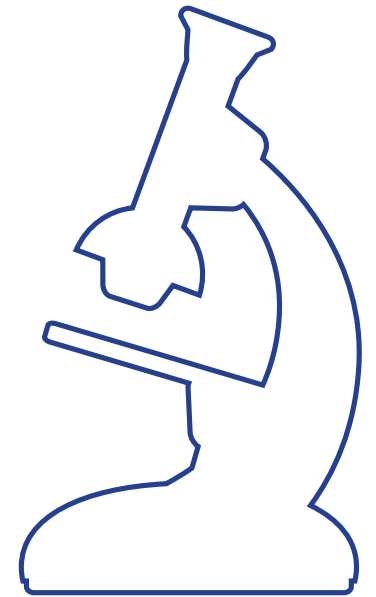
People with HIV can have more of a chance of getting some types of cancer.

For men who have sex with men, changes to the cells in the genitals and anus sometimes cause anal cancer.

This includes changes to cells from the human papilloma virus (HPV), the virus that causes warts. This happens more with HIV-positive men and even more with HIV-positive men with a low CD4 count (that can't fight infections very well). Men over 40 years are advised to talk to their doctor about getting checked for anal cancer.

For women, changes to the cells in the cervix and cervical cancer can happen if you are HIV positive or not. This includes changes to cells from HPV. They happen more often and can be worse in women with HIV. Women with HIV should get a pap smear every year.

Talk to your doctor for more information about these cancers and other types of cancer you may have more of a chance of getting. Ask them if a vaccination for HPV would work for you.



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Dentist

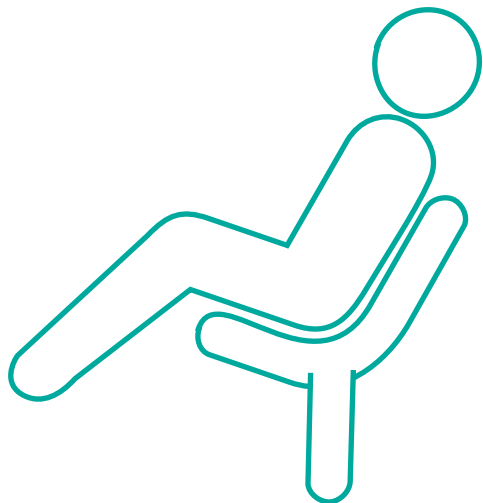
Having HIV and the side effects of some HIV medicines can make you have less saliva in your mouth and cause tooth decay. There is also more of a chance of having gum disease, and even more of a chance in the early stages of HIV. How you are feeling and some HIV medicines can sometimes make you clench and grind your teeth. This can cause your teeth to wear and make them painful.

See your dentist every six to twelve months so they can check these things. They will talk to you about how they can treat them and how you can help stop them.

Talk to your AIDS council or People Living With HIV (PLHIV) organisation about dental plans that may exist.

Dentists are not allowed to give any information about you to anyone else unless you say they can.

If you are not happy with the health care you get, you can complain. The 'Contacts' pages at the back of this book has a list of the Health Service Complaints Commissions in each state.



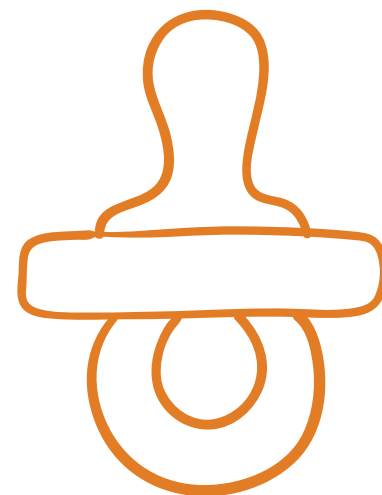
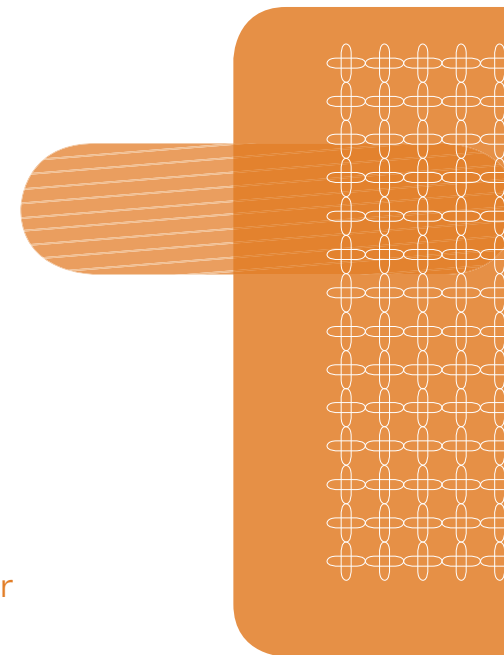
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Having Children

You can still have children if you are HIV positive. But you do need to get the correct information about choosing to have a baby. If you are planning to have a baby or if you have found out that you are pregnant, talk to your doctor as soon as possible.

Whether you are a man or a woman, talk to your doctor about the ways to reduce the chance of passing on HIV to you partner and the baby when you are planning to get pregnant. In Australia most HIV-positive mothers have not passed on HIV to their babies.

Talking to other HIV-positive people who have had children can be helpful. Talk to your doctor or your AIDS council or People Living With HIV (PLHIV) organisation to put you in contact with other HIV-positive men and women who have children.



22

Mental Health

There are many things you can do to help yourself deal with the challenges from HIV. Talking to a counsellor can help or there are places that offer courses to help you learn coping skills. Talk to your doctor or AIDS council or People Living With HIV (PLHIV) organisation to find the best way for you.

A good group of family, friends and other people with HIV can also be helpful.

People with HIV can get depression and anxiety more often. Sometimes the symptoms are not obvious. Each time you see your doctor, talk to them about how you are feeling. They can talk to you about the ways you can get support or treatment if you need to.

Remember that HIV is part of you, but it doesn't define who you are.

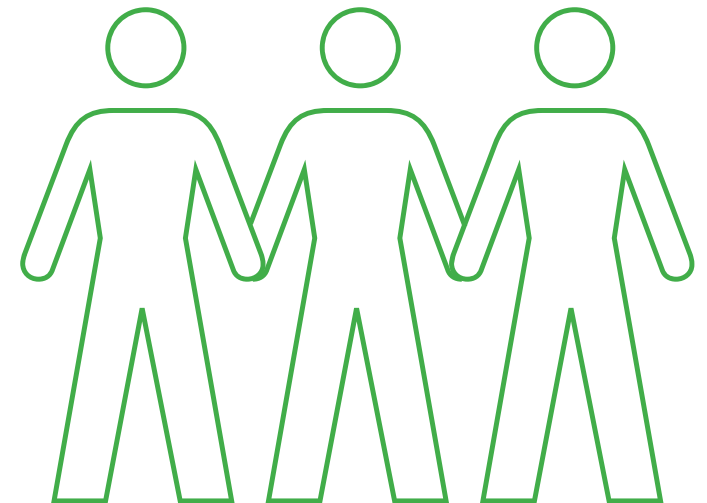


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Social Support

Support from family, friends and other people with HIV can really help. Make sure you have a good group of people to give you support and stay in touch with them.

If you are not comfortable telling people in your community, talk to your AIDS council or People Living With HIV (PLHIV) organisation. They organise different events for HIV-positive people to meet people and make friends. They also organise classes to give you information to help you with your health and well-being. Contact them for more information on these and to find out where you can meet other people with HIV.



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Travel

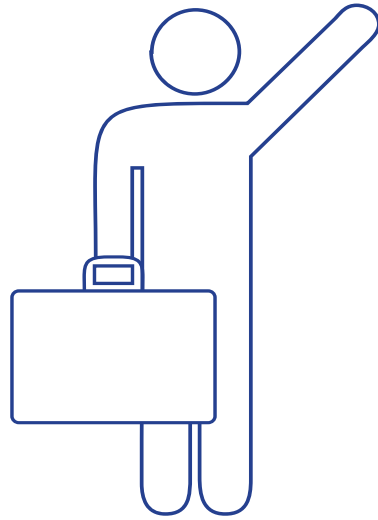
If you are going overseas, there are many countries that you can't go to if you are HIV positive.

Many travel insurance companies need you to tell them if you have any medical issues before you go overseas. This includes if you are HIV positive. Some insurance companies will give travel insurance to HIV-positive people for an extra fee.

Pack enough of your HIV medicines, so you don't stop taking them when you are overseas. Get a letter for your HIV medicines from your doctor to take overseas with you. Pack enough condoms and lubricant. They may not have them where you are going or they might be bad quality. Be careful with what you eat and the water you drink to avoid getting sick.

If you are planning on travelling, talk to your doctor about the vaccinations you can have and leave plenty of time to get them.

For more information about the countries that HIV-positive people can't go to and other things about travelling overseas, you can talk to your AIDS council or People Living With HIV (PLHIV) organisation, or go to www.positivetravel.info.



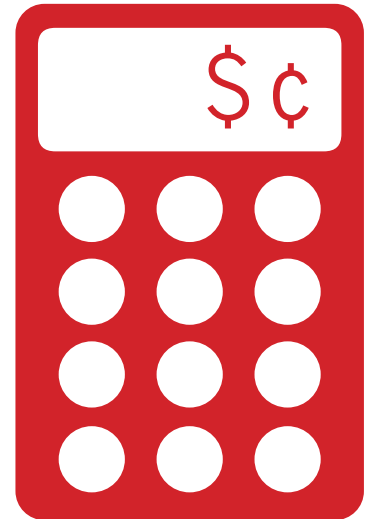
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Money & Planning

HIV medicines can be expensive and some HIV-positive people find it hard paying for their medicines. Some people are finding changes to welfare hard. If you are having problems with money for these or other reasons, there are places that can help.

Organising legal things such as life insurance, and a will or an enduring power of attorney is something that everyone should do, and there are places that can help you with these.

You can talk to places such as the HIV/AIDS Legal Centre (HALC) or Legal Aid organisations (listed at the back of this book) about planning legal issues. You can also talk to your AIDS council or People Living With HIV (PLHIV) organisation about places that can help you with money and legal things.



Contacts

Interpreter Services

Telephone Interpreter Service (TIS)

Phone: 131 450

Multicultural And Related Services

Federation of Ethnic Communities Councils of Australia

www.fecca.org.au/members.cfm
(with links to State and Territory Ethnic Communities Councils)

NEW SOUTH WALES

Multicultural HIV/AIDS and Hepatitis C Service (MHAHS)

www.multiculturalhivhepc.net.au
Phone: (02) 9515 5030
Free call: 1800 108 098 (NSW country)

SOUTH AUSTRALIA

Personal Education and Community Empowerment (PEACE) Multicultural Services

www.rasa.org.au/RASA/MenuBar/Services/PEACE.aspx
Phone: (08) 8245 8100

VICTORIA

Multicultural Health and Support Service

www.ceh.org.au/our_programs/mhss.aspx
Phone: (03) 9342 9700

Alfred Hospital – HIV CALD Service

www.alfredhealth.org.au/hivaidsservice/
Phone: (03) 9076 3942

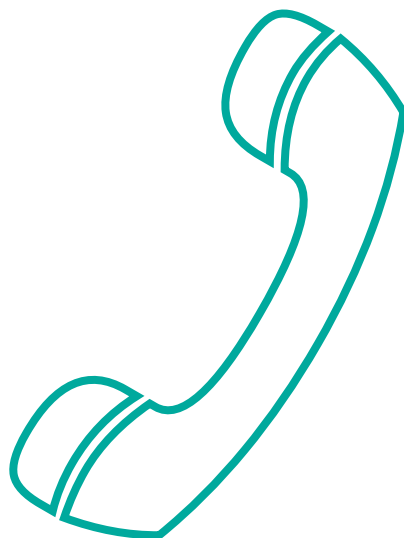
National HIV/AIDS Organisations

Australian Federation of AIDS Organisations (AFAO)

www.afao.org.au
Phone: (02) 9557 9399

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

www.napwa.org.au
Phone: (02) 8568 0300
Free call: 1800 259 666



AIDS Councils And People Living With HIV (PLHIV) Organisations

AUSTRALIAN CAPITAL TERRITORY

AIDS Action Council of the ACT

www.aidsaction.org.au
Phone: (02) 6257 2855

People Living With HIV/AIDS (PLWHA) ACT

www.aidsaction.org.au/content/plwha/
Phone: (02) 6257 4985

NEW SOUTH WALES

ACON

www.acon.org.au
Sydney: (02) 9206 2000
Free call: 1800 063 060
Hearing Impaired: (02) 9283 2088
Northern Rivers: (02) 6622 1555
Hunter/Mid North Coast: (02) 4927 6808
Illawarra: (02) 4226 1163
Positive Living Centre: (02) 9699 8756

Positive Life NSW

www.positivelife.org.au
Phone: (02) 9361 6011
Free call: 1800 245 677

NORTHERN TERRITORY

Northern Territory AIDS and Hepatitis C Council

www.ntahc.org.au
Darwin: (08) 8944 7777
Palmerston: (08) 8931 3676
Alice Springs: (08) 8953 3172

QUEENSLAND

Queensland Association of Healthy Communities

www.qahc.org.au
Brisbane: (07) 3017 1777
Free call: 1800 177 434
Sunshine Coast: (07) 5451 1118
Cairns: (07) 4041 5451

Queensland Positive People

www.qpp.net.au
Phone: 07 3013 5555
Free call: 1800 636 241

Positive Directions

www.positivedirections.org.au
Brisbane: (07) 3900 8000
Free call: 1800 422 313
Gold Coast: (07) 5576 8366
Sunshine Coast: (07) 5441 1222
Townsville: (07) 4721 1384
Cairns: (07) 4051 1028

SOUTH AUSTRALIA

AIDS Council of South Australia

www.acsa.org.au
Phone: (08) 8334 1611
Free call: 1800 888 559
Hearing Impaired: (08) 8362 0306

People Living With HIV/AIDS (PLWHA) SA

www.hivsa.org.au
Phone: (08) 8293 3700

TASMANIA

Tasmanian Council on AIDS, Hepatitis & Related Diseases

www.tascahhd.org.au
Phone: (03) 6234 1242

VICTORIA

Victorian AIDS Council/Gay Men's Health Centre

www.vicaids.asn.au
Phone: (03) 9865 6700
Free call: 1800 134 840
Positive Living Centre: (03) 9863 0444
Free call: 1800 622 795

People Living With HIV/AIDS (PLWHA) Victoria

www.plwhavictoria.org.au
Phone: (03) 9865 6772

WESTERN AUSTRALIA

WA AIDS Council

www.waids.com
Phone: (08) 9482 0000

Organisations To Help You Give Up Smoking

Quitnow

www.quitnow.info.au
Quitline: 13 7848 (13 QUIT)

Cancer Council Australia

www.cancer.org.au (with links to state and territory Cancer Councils)
Cancer Council Helpline: 13 11 20

Legal Assistance

HIV/AIDS Legal Centre

www.halc.org.au
Phone: (02) 9206 2060
Free call: 1800 063 060
Hearing Impaired: (02) 9283 2088

AUSTRALIAN CAPITAL TERRITORY

Legal Aid ACT

www.legalaidACT.org.au
Phone: (02) 6243 3471
Information line on 1300 654 314

NORTHERN TERRITORY

Northern Territory Legal Aid Commission

www.ntlac.nt.gov.au (with links to contact details of offices in Northern Territory)
Legal Information Telephone Line: 1800 019 343

NEW SOUTH WALES

Legal Aid NSW

www.legalaid.nsw.gov.au (with links to contact details of offices in New South Wales)
Phone: 1300 888 529
Hearing Impaired: 1300 889 529

Law Access NSW

www.lawaccess.nsw.gov.au
Phone: 1300 888 529
Hearing Impaired: 1300 889 529

QUEENSLAND

Legal Aid Queensland

www.legalaid.qld.gov.au
Phone: 1300 65 11 88
Indigenous Information Line: 1300 650 143
Hearing Impaired: (07) 3238 3023

SOUTH AUSTRALIA

Legal Services Commission of South Australia

www.lsc.sa.gov.au (with links to contact details of offices in South Australia)
Legal Advice and Information: 1300 366 424

TASMANIA

Legal Aid Commission of Tasmania

www.legalaid.tas.gov.au (with links to contact details of offices in Tasmania)
Legal Advice and Information: 1300 366 611

VICTORIA

Victoria Legal Aid

www.legalaid.vic.gov.au (with links to contact details of offices in Victoria)
Legal Information Service: (03) 9269 0120, 1800 677 402 (Country Callers)

WESTERN AUSTRALIA

Legal Aid Commission of Western Australia

www.legalaid.wa.gov.au (with links to contact details of offices in Western Australia)
Hearing Impaired: 1800 241 216

Health Services Complaints Commissions

AUSTRALIAN CAPITAL TERRITORY

ACT Human Rights Commission

www.hrc.act.gov.au
Phone: (02) 6205 2222
Hearing Impaired: (02) 6207 0525

NEW SOUTH WALES

Health Care Complaints Commission

www.hccc.nsw.gov.au
Phone: (02) 9219 7444
Free call: 1800 043 159
Hearing Impaired: (02) 9219 7555

NORTHERN TERRITORY

Health and Community Services Complaints Commission

www.hcsc.nt.gov.au
Phone: (08) 8999 1969
Free call: 1800 806 380

QUEENSLAND

Health Quality and Complaints Commission

www.hqcc.qld.gov.au
Phone: (07) 3120 5999
Free call: 1800 077 308
Hearing Impaired: (07) 3120 5997

SOUTH AUSTRALIA

Health and Community Services Complaints Commissioner

www.hcsc.sa.gov.au
Phone: (08) 8226 8666
Free call: 1800 232 007
Hearing Impaired: 133 677 then ask for (08) 8226 8666
Hearing Impaired (Country callers): 1800 555 677 then ask for 1800 232 007



TASMANIA

Health Complaints Commissioner

www.healthcomplaints.tas.gov.au
Free call: 1800 001 170

VICTORIA

Health Services Commissioner

www.health.vic.gov.au/hsc/
Phone: (03) 8601 5200
Free call: 1800 136 066
Hearing Impaired: 1300 550 275

WESTERN AUSTRALIA

Office of Health Review

www.healthreview.wa.gov.au
Phone: (08) 9323 0600
Free call: 1800 813 583
Hearing Impaired: (08) 9323 0616





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For more copies of this resource,
please contact your local AIDS Council
or People Living With HIV Organisation.

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