



FEATURING

Ita Buttrose

AO, OBE

Australian of the Year 2013

HIV Awareness Advocate



being positive



HEALTHY LIVING FOR AUSTRALIANS WITH HIV

JI
Olympic athlete



DIANNE
Mother of four



TOBIN aka
Vanessa
Performer,
Activist and
HIV Educator



Contents

- 2 Introduction
- 4 What is HIV?
- 6 How Can You Get HIV?
- 7 How is HIV Different from AIDS?
- 7 What Does It Mean to be HIV Positive?
- 8 Testing for HIV
- 10 I Just Found Out I Have HIV. What Should I Do?
- 12 Telling Other People
- 13 Treatments for HIV
- 14 How Do I Know My Treatment is Working?
- 15 Stick With It!
- 16 Lifestyle and Emotional Issues
- 18 Enjoy a Great Sex Life!
- 19 Post-Exposure Prophylaxis (PEP)
- 20 Final Thoughts
- 22 Resources
- 23 Credits

Inside back cover:

Being Positive: Healthy Living for Australians with HIV
DVD (26 minutes)

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Introduction



Learning that you or a loved one has HIV can be both scary and confusing. What is HIV, actually? What does it mean to have it? What does the future hold? These questions, and the unsettled feelings that can go with them, are normal. The good news: the more you learn about HIV, the more confident you'll feel, and the more hopeful you'll be about the years to come. A key message, right up front, is that you're not alone.

Even though Australia has one of the lowest rates of HIV infection in the world, about 1,000 people are diagnosed with HIV in Australia each year. About 21,000 Australians are currently living with HIV. That translates into a lot of support, both for those with HIV and those who love them.

A key message is that you're not alone.

A second key point is that, today, there is hope. With modern treatments, people with HIV can expect to live a normal and healthy life. They can expect to live just as long, on average, as people who don't have HIV.

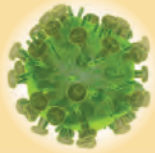
This booklet and DVD programme are for people who have recently learned they have HIV, as well as for their partners, friends, and family. By reading the booklet and watching the DVD, you'll learn more about HIV, your treatment options, and ways to live a healthier life. In addition, you'll learn from other Australians who are living well with HIV.



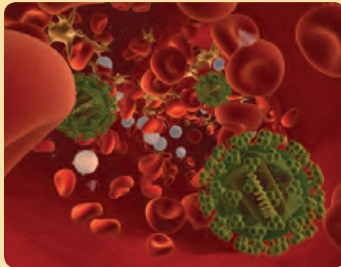
Although it can be frightening at first, many people with HIV find that their diagnosis is actually an opportunity. An opportunity for better health. An opportunity for new connections. An opportunity for growth. With the right information and good medical support, you can seize these opportunities and effectively manage HIV.



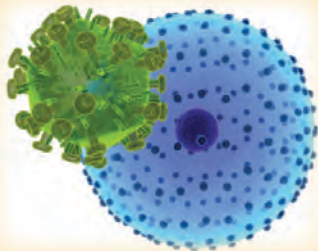
What is HIV?



HIV is a virus



HIV enters the blood



HIV targets, enters and damages CD4 cells (T cells)

HIV stands for *human immunodeficiency virus*. The virus, if not treated, can attack your body's normal defences—the immune system.

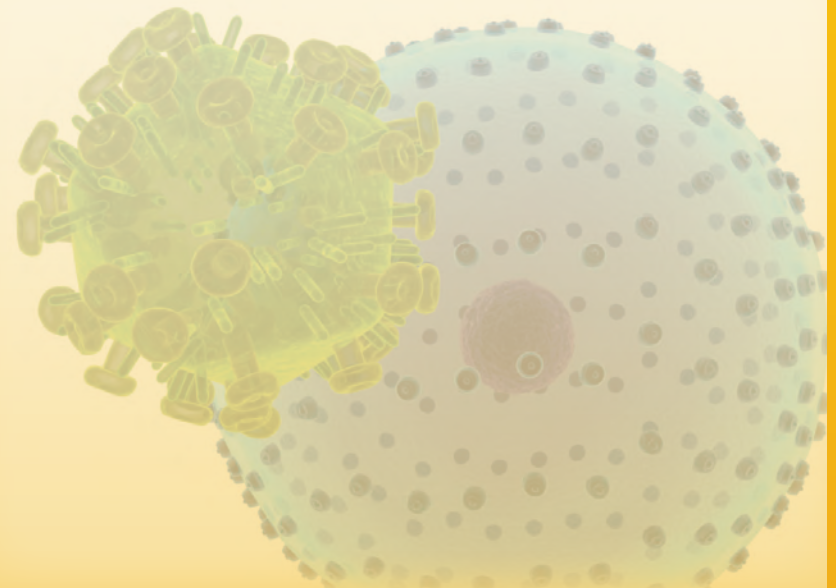
HIV targets a key part of that system: CD4 cells, also called T cells. If enough of these cells are damaged, you can't protect yourself from infections and diseases.

HIV

Up to 20% of people who have HIV don't know it.

Many people do not know they have HIV, because they do not feel sick or notice any symptoms. Many people do feel flu-like symptoms 2 – 12 weeks after they first get the virus, but some people have no symptoms at all. Even if you don't feel anything, however, the virus is at work. In fact, the time right after a person has been infected is when they are most likely to spread the virus to others, because HIV is present in large quantities in some body fluids.

Since HIV can “hide” in your body for many years, you might give the virus to somebody else without meaning to. That's why it's so important to get tested for HIV, if you have any reason to suspect you might have been exposed to the virus. Up to 20% of people who have HIV don't know they are infected with the virus.



How Can You Get HIV?

HIV is actually a very fragile virus. It cannot live long outside the body. You can't get HIV by shaking hands or hugging or a casual kiss. It must be passed directly from one person's body to another through blood, semen, or vaginal secretions. The virus has never been shown to be passed by saliva, sweat, or tears.

In Australia, HIV is mainly transmitted between men who have sex with men, although 1 in 4 new cases of HIV infection occur via heterosexual contact. The most common way to get HIV is by having unprotected anal or vaginal sex with someone who has HIV. Oral sex probably poses less risk, unless someone has cuts or sores in their mouth (e.g., due to a recent visit to the dentist).



Another way you can get HIV is by sharing needles and syringes used to inject drugs. And mothers with HIV may pass the virus to their baby during pregnancy and childbirth, or through breastfeeding if the mother is not on HIV treatment.



The most common way to get HIV is by having unprotected anal or vaginal sex with someone who has HIV.



How is HIV Different from AIDS?

AIDS stands for *Acquired Immunodeficiency Syndrome*. AIDS is the disease that can be caused by HIV. HIV and AIDS are not the same!

Many people have HIV but do not have AIDS. AIDS is also not a single disease. It is a single name for a wide range of conditions that may occur when a person's immune system is seriously damaged by HIV. Today, with modern treatments and care, people with HIV are unlikely to develop AIDS.

What Does It Mean to be HIV Positive?

If tests show that you have HIV in your body, you are said to be "HIV-positive." If you do not have HIV, you are "HIV-negative."

It's important to know that being HIV-negative does *not* mean you can't be infected. You must get re-tested if you think you may have been exposed to the virus, and you should continue to use safer sex techniques, such as using condoms.

Testing for HIV

If HIV enters the body, the immune system starts to produce *antibodies*—substances that help you fight off infections. It can take months for your body to produce enough antibodies to be detected by a test. Some HIV tests look for HIV antibodies, while others detect the virus particles themselves. You can request an HIV test at any GP or sexual health clinic.

Getting tested for HIV is easier and faster than it used to be.

HIV antibodies can now be detected in a small sample of blood obtained by a 'finger prick' or in a sample of saliva obtained by using a swab in the mouth. This is called 'Rapid Testing.' Results from a rapid test are available within 30 minutes to an hour. If a rapid test is positive, it will be confirmed by a more thorough test done in a laboratory. You can use the Resources at the back of this booklet to find a rapid testing service near you.



Although 'home testing kits' are available from sources in Australia and overseas, they are not recommended. It is important that HIV testing be performed in a setting where people can get support and counselling if they need it.

Even though HIV testing rates in Australia are higher than many other countries, it is thought that between 10% and 20% of Australians living with HIV have *not* been tested. That means these people do not know they are carrying the virus and could spread it to others.

It's vital for people to get tested for HIV so that, if they test positive, they can:

- Take steps to prevent passing on HIV to others
- Take advantage of new treatments that help people who are HIV-positive remain healthy, and lower the chance of passing the virus on to others



I Just Found Out I Have HIV.

What Should I Do?

First of all, take a deep breath. You are not in any immediate danger. You've already taken the next step—getting more information—by reading this booklet! Next, you should find a doctor who is qualified and experienced in caring for people with HIV. In Australia, doctors need to have special training to



be able to work with people who have HIV. If you have been diagnosed by a doctor who doesn't have this training, he or she should refer you to an HIV specialist.

It is important that you get on well with your doctor, and that you feel comfortable talking with her or him. Remember that conversations with a doctor are private. Your medical information will be kept safe and can only be shared with your permission.

Another thing to do right away after being diagnosed with HIV, is to get tested for other kinds of sexually transmitted infections (STIs). Not only can STIs make you sick, they can make it easier for HIV to pass from one person to another. Even if you feel fine and don't have any symptoms, you may still have an STI and pass on the infection, especially if the infection is in the anus or throat. Testing is the only way to know. STIs can progress more rapidly in HIV-positive people and, if left untreated, they can seriously damage your health.

Find a doctor who is qualified and experienced in caring for people with HIV.



Telling Other People

It's important to talk about your diagnosis with somebody—everybody needs that kind of support. But before you tell other people about your HIV status, think about who *needs* to know, and who does *not* need to know. Take your time about this. Once you have told someone, you can't take it back! Be especially careful about disclosing your status online. The people you tell may want to ask you many questions, and sometimes this can be stressful. In addition, some people have outdated information



and negative views about HIV, and their responses may not be helpful.

Different states in Australia have different laws about whether you must share your HIV status with past or current sex partners. Find out about the laws in your state.



Think about who needs to know, and who does not need to know.

In certain instances, an HIV-positive person who exposes another person to HIV or transmits HIV may be guilty of a criminal offence. Talk to your local community legal centre or HIV organisation to learn more about your rights and responsibilities. (See some of the organisations listed at the back of this booklet.)

Treatments for HIV

Modern HIV treatments allow people with HIV to be healthier than ever and live just as long, on average, as people who do not have HIV. This wasn't always the case. When HIV was discovered, in the early 1980s, there were no treatments to fight the virus. But many drugs have been developed since then to treat HIV.

Recent guidelines recommend that people with HIV start treatment sooner than was recommended in the past. This can have a number of health advantages, but it's a decision that must be made carefully. You should have all the information you need. Don't be afraid to ask lots of questions!

HIV medicines usually work best when several are used together. Modern combinations involve taking only a few tablets once or twice a day; some people take only one tablet per day. Your doctor and other people involved in your health care can help you find the treatments that are best for you.

Modern HIV treatments allow people with HIV to be healthier than ever.



Stick With It!

HIV treatments work best when you take them exactly as directed by your doctor, and do not miss any doses. Many people use phone alarms or pill boxes to remind them when to take their medicines. Try keeping your medicines somewhere you will see them when it is time to take them, maybe with your breakfast cereal. You may also want to keep extra medication 'on hand' in case you miss a dose, or want to go out, or need to travel on short notice.



You can keep backup supplies of your medicines at work, in your backpack, or handbag. There are smaller pillboxes designed for this purpose. Plan ahead for weekends, holidays, and changes in your routine. Some people get their partners, flatmates, or other support people to remind them about medicines. You don't want to run out, so keep track of your supply and contact your doctor or pharmacy when you need a new script.



If you experience any unusual or bothersome side effects from your medicine, talk to your doctor. There are many different medicines available, and switching treatments may reduce your side effects.



How Do I Know My Treatment is Working?

When HIV treatment works, it stops the virus from reproducing, so the total amount of virus in your body should drop. This is called your "viral load"—your doctor will test for it regularly. Your viral load is the main measure of treatment success.

HIV medicines frequently reduce the level of HIV in your body to undetectable levels. This is a very good thing! It means you and your immune system can stay healthy. But having undetectable HIV in your blood does *not* mean you are fully cleared of HIV; HIV can sometimes still be detected in semen and vaginal fluids. It may still be possible to pass on HIV, even if you have undetectable levels in your blood. "Undetectable" simply means that laboratory tests are not powerful enough to detect a low viral load.

Lifestyle and Emotional Issues

It can take some time to adjust to learning you are HIV-positive. Take advantage of support offered by partners, family, your doctor, or even a professional counsellor. Finding one or more people with whom you can be totally open and comfortable can be extremely helpful. Ask your local HIV organisation about support groups or opportunities for online discussions.

Watch out for signs of a “down” or depressed mood. It’s normal to be a little blue when you’re first diagnosed. But if your feelings seem to be lasting a long time, or if they are getting in the way of normal activities, talk to your doctor about it. Signs of depression include sleep difficulties, weight gain or loss, restlessness, lack of energy, and—most importantly—a feeling that nothing gives you pleasure anymore.

You need to take care of yourself physically as well. This starts with eating a healthy diet. You don’t need any special diets, just use common sense. Eat a balance of whole grains, fruits, vegetables, and protein-rich foods such as meats, fish, eggs, and dairy products. Avoid high-sugar foods that have few nutrients, such as sugary drinks, sweets, and high-carb snack foods.



Here are some other tips for keeping your body in top form:

- If you smoke, think about quitting
- Get enough sleep (typically this means 7-8 hours each night), and talk to your doctor if you are having trouble sleeping
- Exercise regularly (30 minutes a day at least)
- Don’t drink alcohol to excess
- Explore ways to reduce stress, such as meditation, yoga...even laughter!



Enjoy a Great Sex Life!

Some people who are HIV positive are turned off sex because they worry about passing the virus to others. But sex is an important and normal part of life. You don't have to give up physical intimacy because of HIV. You just have to be careful.



Here are some strategies known to reduce the risk of passing HIV:

- Always use condoms, and always use them with water- or silicon-based lube
- Don't share sex toys, or wash them thoroughly between uses
- If you are on HIV treatment, talk to your doctor before using erection-enhancing medicines
- Avoid excessive alcohol—it interferes with the sexual response of both men and women and may cloud your judgement
- Avoid genital piercings of any kind. Un-healed piercings can allow HIV into your body.



Post-Exposure Prophylaxis (PEP)

Accidents happen. If a condom breaks, or if you think you or a partner has done something that raises the risk of HIV infection, there are medicines that can lower that risk. These medicines are called *post-exposure prophylaxis* (PEP). PEP is a combination of at least 2 anti-HIV drugs, taken for 4 weeks. PEP is most effective when taken within hours of being exposed to HIV, though it may still be effective if started up to 72 hours after exposure. If used exactly as prescribed, PEP is highly likely to prevent HIV infection, though it is not 100% reliable. Contact a doctor or go to a hospital emergency department immediately, if you think you or a partner may have been exposed to HIV.

Final Thoughts



Although testing positive for HIV can be scary at first, you now know what to do. You've learned that today, HIV can be managed successfully with the right treatments. People with HIV can lead healthy lives and have a normal life expectancy. The choices you make about treatment, testing, diet, exercise, and other lifestyle issues can help your body and mind cope more effectively with HIV.

If you or a loved one has recently been diagnosed with HIV, ask questions, get answers, and start a conversation with a doctor who has experience in treating HIV-positive patients. Connect with others, and take advantage of the many kinds of support offered by Australian organisations dedicated to helping those with HIV. You've already made a great start by reading this booklet. Now it's time to put your knowledge into action!

BEING POSITIVE

People with HIV can live a normal and healthy life.

Resources

AIDS Action Council of the ACT
aidsaction.org.au

AIDS Council of New South Wales (ACON)
acon.org.au

Australasian Society for HIV Medicine
ashm.org.au

Australian Federation of AIDS Organisations
afao.org.au

Australian Institute of Health and Welfare
aihw.gov.au

Living Positive Victoria
livingpositivevictoria.org.au

Multicultural HIV/AIDS and Hepatitis C Service (MHAHS)
multiculturalhivhepc.net.au

National Association of People With HIV Australia
napwha.org.au

Northern Territory AIDS and Hepatitis C Council
ntahc.org.au

Positive Life NSW
positivelife.org.au

Positive Life South Australia
hivsa.org.au

Positive Women Victoria
positivewomen.org.au

Queensland Positive People
qpp.net.au

Straight Arrows
straightarrows.org.au

Tasmanian Council on AIDS, Hepatitis & Related Diseases
tascahrd.org.au

The Kirby Institute for Infection and Immunity in Society
kirby.unsw.edu.au

Victoria AIDS Council
vic aids.asn.au

Western Australian AIDS Council
waaids.com

Credits

Being Positive: Healthy Living for Australians with HIV was made possible through the expertise, funding, time, and efforts of many contributors.

PRESENTERS

Australasian Society for HIV Medicine

The Australasian Society for HIV Medicine (ASHM) is an organisation of health professionals in Australia and New Zealand who work in HIV, viral hepatitis and sexually transmissible infections. ASHM draws on its experience and expertise to support the health workforce and to contribute to the sector. ASHM supports its members, sector partners and collaborators to generate knowledge and action in clinical management, research, education, policy and advocacy in Australasia and internationally. It is committed to quality improvement and its products and services are sought after by governments, members, health care workers and affected people. ASHM is not religiously or politically affiliated.



National Association of People With HIV Australia

Founded in 1989, The National Association of People With HIV Australia (NAPWHA) is Australia's peak non-government organisation representing community-based groups of people living with HIV. NAPWHA provides advocacy, effective representation, policy, health promotion and outreach on a national level. Our work includes a range of health and education initiatives that promote the highest quality standard of care for HIV positive people. NAPWHA contributes to clinical and social research into the incidence, impact and management of HIV. We strive to minimise the adverse personal and social effects of HIV by championing the participation of positive people at all levels of the organisation's activity.



Positive Life NSW

Positive Life NSW is a non-profit community organisation that promotes a positive image of people living with and affected by HIV with the aim of eliminating prejudice, isolation, stigmatisation and discrimination. We provide information and targeted referrals, and advocate to change systems and practices that discriminate against people with HIV, their friends, family, and carers in NSW.



The Royal Australian College of General Practitioners (RACGP)

The Royal Australian College of General Practitioners (RACGP) is the specialty medical college for general practice in Australia, and the largest professional general practice organisation in Australia. The RACGP represents over 21,500 members working in or towards a career in general practice and is proud that more than 19,300 Australian-registered general practitioners have chosen to be a member of the College.

The RACGP is responsible for defining the nature of the discipline, setting the standards and curriculum for education and training, maintaining the standards for quality clinical practice, and supporting general practitioners in their pursuit of excellence in providing high quality health care to Australian communities.



The Royal Australian
College of General
Practitioners

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We have a proud heritage in our founder Dr Paul Janssen who established the company with a strong grounding in science and innovative solutions, always putting patients first. Driven by our commitment to patients, we develop sustainable, integrated healthcare solutions by working side-by-side with healthcare stakeholders, based on partnerships of trust and transparency.

We also provide a broad base of strong support for a range of causes, communities and charities. In Australia we work closely with the Salvation Army, St Vincent de Paul and Mary MacKillop East Timor Mission to make a positive difference in the community.

More information can be found at www.janssen.com.au



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Ita Buttrose

AO, OBE
Australian of the Year 2013
HIV Awareness Advocate

CONTRIBUTORS TO THE DVD

Dr. Kate Clezy, MBBS, FRACP

Director, Infectious Diseases Department
Prince of Wales Hospital
Randwick NSW
Fellow, The Royal Australasian College of Physicians

Dr. Dick Quan, MBBS

Director, Holdsworth House Medical Practice
Director, Holdsworth House Dental Practice
Sydney and Byron Bay
Member, The Royal Australian College of General Practitioners

Project Manager
Carol Brandenburg
Executive Producer
Conrad Productions

Guidebook Author
Stephen R. Braun
Medical Writer
braunmedicalmedia.com

Guidebook Design
Cinda Debbink
Design Partners
dgdesignpartners.com

Program Research and Development
Elizabeth T. Conrad, MD DABFM

Ita Buttrose photos courtesy of Ross Coffey

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The 26-minute companion documentary presents real stories of three Australians who are HIV positive and living full, healthy lives.



Expert medical commentary—from an infectious disease specialist, and a practitioner who specialises in treating HIV/AIDS—is included in the programme.

Australian of the Year (2013) Ita Buttrose, AO, OBE is also featured. She is a longtime HIV Awareness Advocate.



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DVD
INSIDE

being positive

HEALTHY LIVING FOR AUSTRALIANS WITH HIV

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The good news? With modern treatments, people with HIV can expect to live a normal and healthy life. They can expect to live just as long, on average, as people who don't have HIV!

Whether you just found out today that you're HIV-positive, or you've known for years, the information in this programme will lay a foundation for progress.

You'll learn:

- More about HIV and AIDS
- What to do if you are HIV-positive
- Where to find help
- What treatments are available to help you stay healthy

alan
Weiss
productions

