

# The Management of HIV/AIDS

A resource guide for Indigenous  
primary health care organisations



**ANCAHRP**

Australian National Council on AIDS, Hepatitis C and Related Diseases

## Acknowledgments

In September 1996, the Australian National Council on AIDS and Related Diseases (ANCARD) Indigenous Australians' Sexual Health Working Party proposed that a resource manual on how to care and support Indigenous peoples with HIV and their carers be developed. The Resource Manual would enable people directly affected by HIV/AIDS to influence service providers on their care and support issues. It would be based on the simple premise that Indigenous people who have HIV/AIDS have the right to the best possible care and support in the community or setting of their choice.

Subsequently, a small group of Indigenous people who were infected and affected by HIV/AIDS were brought together by the then Office for Aboriginal and Torres Strait Islander Health Services, Department of Health and Family Services, to workshop the range of issues that could be incorporated into such a manual.

This was the first time such a group of people had been brought together. All the people in the group had a great deal of experience and knowledge of HIV/AIDS and Indigenous culture, society and lifestyles.

For many reasons people in the group wish to remain anonymous. They know who they are, for it is their important and invaluable contributions that has made this publication possible.

Organisations represented by this group included the National Association of People Living With AIDS (NAPWA), the Australian Federation of AIDS Organisations (AFAO), the AIDS Council of SA (ACSA) and the Australian National Council on AIDS Related Diseases (ANCARD) Indigenous Australians Sexual Health Working Party (IASHWP).

Ms Kerry Arabena facilitated the two workshops, held in December 1996 and March 1997. She was responsible for collating the issues and ideas from the workshop participants to produce the initial working document. This publication is a credit to Ms Arabena's commitment to sexual health issues amongst the Indigenous communities of Australia.

The Working Party would like to thank and recognise the hard work of those who participated in the development of this excellent guide.

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## Preface

As a group of Indigenous people brought together to consider the issues relating to the sexual health of Indigenous Australians, we recognise Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) as a major health care threat to Indigenous communities, and acknowledge that many Indigenous peoples are still living and dying alone and in shame of AIDS. This must stop.

Historically, there has already been a significant contribution from dedicated Indigenous peoples in responding to this epidemic. Our losses have been great but through our collective communities we have continued to survive and have become stronger.

We acknowledge these pioneers who set the standards for our collective communities to understand and strive for acceptance, tolerance and life. The early pioneers in this struggle were largely Indigenous gay and lesbian people who were and are HIV/AIDS infected and affected people, and the educators and carers who unselfishly gave of themselves.

Though we face many dilemmas and barriers to affordable health care for all Indigenous peoples this group is working to empower our community groups and individuals with this manual for the future survival of all Indigenous people.

We hope this document, which reflects our collective personal experiences, can be used as a tool for all groups. HIV/AIDS and sexual health are issues that affect us all. Through adoption of safer practices that can reduce the risk of getting infected with HIV, other sexually transmitted infections (STI's) and hepatitis C, we can promote healthier lifestyle choices and options that are relevant and acceptable to all Indigenous people.

As we enter the next millennium there are many new treatments and approaches to combat STI's that give us hope and encouragement for the future. While there is no cure for HIV, there are now new treatments that slow down the disease for some time in many infected people. Nevertheless, these new treatments must be accessible and affordable to all peoples, regardless of race, gender, age, sexuality and location.

**There is no room for complacency, now is the time to act.**

Individuals and groups should be actively encouraged and supported by primary health care givers throughout the whole process of seeking and receiving treatment, care and support.

As people both infected and affected by HIV/AIDS we ask that our basic human rights be respected, that we not be treated as lepers, and that all service delivery is user friendly. Information sharing is a two-way street, and as we take responsibility for our actions, we invite others to do the same. We encourage and acknowledge the diversity of Indigenous communities. Community means many things to many people. We support the notion that community is inclusive and not exclusive.

That means working together without fear of discrimination or reprisal for the maintenance and survival of all Indigenous peoples.

Indigenous communities are diverse social and geographic environments, spanning city, suburban, rural, fringe camp, remote and island settings. Attitudes and beliefs regarding HIV/AIDS and caring for infected persons are diverse and the levels of access to relevant services differ (Hill & Murphy 1992).

Many people in Indigenous communities still fear and misunderstand HIV/AIDS. Consequently, some Indigenous people living with HIV/AIDS are leaving their communities to find care and support services in the larger cities. Apprehension still exists about breaches of confidentiality, and possible discrimination against HIV positive people, people living with AIDS and their families. Much needs to be done to improve the current fragmented approach to HIV care and support options for Indigenous Australians.

The National Indigenous Australians' Sexual Health Strategy 1996-97 to 1998-99 (NIASHS) was written after community consultations across the country. This was overseen by the ANCARD Indigenous Australian's Sexual Health Working Party (IASHWP). It identified that the care and support needs of Indigenous people living with HIV/AIDS were not being adequately met.

Anecdotal evidence suggests that Indigenous people living with HIV/AIDS are being cared for by families and community networks, which in turn are not adequately supported. Moreover, the NIASHS emphasises the importance of Aboriginal Health Services having sufficient information to provide good quality services to their clients with HIV/AIDS.

The NIASHS concludes that Indigenous Australians with HIV/AIDS are not being diagnosed early, are not receiving the latest information on treatment options that slow down HIV progression, and are not being included in clinical trials of new treatments. The report identifies the need for better coordination between care and support services and for the diversity of circumstances of Indigenous peoples living with HIV/AIDS to be addressed. The Government has developed this manual as one key response to the ANCARD Working Party findings and conclusions regarding care and support.

While this manual raises issues specifically relating to HIV and AIDS, it is important to recognise that the problem of HIV/AIDS cannot successfully be addressed in isolation from other sexually transmitted infections and other related blood-borne viruses, and issues such as sexuality and injecting drug use. The ANCARD Working Party found that to address HIV effectively, a comprehensive approach to overall Indigenous sexual health is needed. Two major risk factors identified in the NIASHS intensify the need for a holistic approach to HIV/AIDS:

- Sexually transmitted infections (STI's) in Indigenous communities, STI's can play a significant role in assisting the transmission of HIV; and
- The rates of STI's among Indigenous communities are affected by the lack of access to effective diagnosis and treatment services.

## Why should we worry about HIV and AIDS?

HIV and AIDS is a crucial health issue because it is a relatively new epidemic which, most commonly, is transmitted from one person to another through sexual and drug injecting behaviours. Already HIV has infected millions of people around the world, many have developed AIDS. There is no cure for HIV or AIDS, and the long time period between infection and symptoms increases the potential for people to unknowingly transmit HIV (Read 1996). During this time the HIV infection can be described as "invisible". Consequently, the potential for an even greater number of people to become infected by HIV and affected by HIV and AIDS is very high.

The number of Indigenous Australians already infected with HIV might seem small at present, but these numbers have not declined over time. Recent research on the epidemiological patterns of newly diagnosed HIV infection and AIDS in Aboriginal and Torres Strait Islander communities from 1992 to 1998 indicates that the rates of HIV diagnosis amongst the Indigenous population remain relatively stable (Gutherie et al, 2000).

In every country in the world this is how the HIV epidemic begins. The countries that have managed best are those that respond quickly and boldly. Responding to HIV in Indigenous communities involves many challenges. Responses need to take account of the unique circumstances, in which Indigenous people live and practice their culture.

Above all, in meeting the challenges of HIV/AIDS, we need to face up to our own preconceptions, prejudices and behaviours.

## What effects are felt by individuals, families and communities?

The tragic impact of the AIDS epidemic has the potential to further erode the social and economic fabric of Indigenous communities. Many of those who get infected with HIV are at a stage in their lives where they have a significant role in maintaining the community, are raising children and have established households and dependants to support (Aboagye-Kwarteng & Moodie 1995). Indigenous peoples are at particular risk of HIV infection due to existing high rates of STI's and their lack of access to effective services (DHFS 1997). Though rates of HIV are currently stable, even these rates will sadly diminish and drain the family and community base in many Indigenous settings.

The impact of AIDS among low-income groups is especially devastating. Poorer families have no margin to absorb the costs of health care, or the loss of earnings. The cost of the HIV epidemic will fall most heavily on the poor, further entrenching their poverty and amplifying existing socioeconomic inequity (Aboagye-Kwarteng & Moodie 1995). With the onset of the more debilitating symptoms of HIV/AIDS, affected individuals and families may no longer be able to work productively, causing a decrease in the family income at the same time as their emotional, social, economic and health needs intensify.

## Why is care and support an urgent issue?

Establishing ways to care for and accommodate an Aboriginal or Torres Strait Islander person living with HIV/AIDS and understanding their needs requires urgent attention by service providers dealing with Indigenous communities. Consultations undertaken by the Working Panel on Aboriginals, Torres Strait Islanders and HIV/AIDS in 1989 (DHCS 1989) revealed that the majority of communities would not reject one of their own people who were infected. As one community leader put it, "We live together, we cry together and we bury our dead together". These communities have indicated they want to care for, and support, their own people infected with HIV/AIDS but lack the basic knowledge and resources to do this adequately. There is little evidence to suggest that the situation has changed in many places since these consultations were conducted in 1989.

Some Indigenous Health Services have worked closely with their communities to develop innovative and locally relevant care and support resources, but there is a long way to go. Fortunately, a number of valuable lessons can be learned from observing the response to HIV/AIDS in non-Indigenous communities. These lessons can be used in planning services for Indigenous people and communities.



## About this manual

This manual is designed for use by Indigenous primary health care organisations. It aims to increase awareness amongst health workers in Indigenous primary health care organisations of the needs of Indigenous people infected and affected by HIV/AIDS. It is hoped that increased awareness will promote local service planning in relation to HIV and facilitate the development of HIV policies and management plans. This will then assist the community to understand more about HIV, allowing those affected by HIV to be better accepted and supported.

The manual is not intended to duplicate any existing regional guidelines around HIV but to encourage organisations to review their preparations for handling the broad range of complicated issues associated with HIV and AIDS. Some services have never managed clients (Indigenous or non-Indigenous) with HIV/AIDS, whilst others have extensive and well established support networks.

The manual provides clear and useful information that will assist in planning and designing effective care and support services.

Another valuable resource is *STD Control in Remote Aboriginal Communities - A Manual for Clinic Workers* (DHAC 1999). There are many areas of overlap with this manual and the two can be used together in establishing good policies and services.

An important element in understanding HIV and developing effective care and support programs is the involvement of those with HIV and their carers. That is why this manual constantly stresses the importance of the relationship between people living with HIV and service providers.

The time to develop overall STI and HIV policies and protocols is before the impact of an epidemic is felt on a services work, staff, clients and community.

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# Chapter 1

## Basic facts about Human Immunodeficiency Virus (HIV)

### What is HIV?

HIV stands for Human Immunodeficiency Virus. HIV is different from AIDS. HIV infects and destroys white blood cells (called CD4+ T-lymphocytes or CD4 T-cells) which are an integral part of the human immune system. The immune system is the body's main method of fighting infection. By killing or damaging the cells of the immune system, HIV steadily destroys the body's ability to fight infections and certain cancers. Because the body's resistance is weakened, unusual infections occur (opportunistic infections) and some types of cancers develop. As well, the HIV virus can cause specific diseases of its own. At the later stages of HIV infection, the body's resistance is profoundly weakened and AIDS occurs.

There is no cure for HIV. People cannot be vaccinated against HIV. Scientists are working on both a cure and vaccines, but expect it will be a long time yet before a cure or vaccine is developed. Recently, scientists have found new treatments that appear to slow down the growth of the virus.

### How is HIV transmitted?

#### Principles of transmission

Five principles have been identified in order for viral transmission to occur (AFAO 1991). All of these conditions must exist in order for an infection to occur.

1. A source of infection (i.e. presence of HIV).
2. A means of transmission (i.e. unprotected sex, sharing of injecting equipment etc).
3. A host susceptible to the infection (only humans can be infected with HIV).
4. A route of entry to the host and target cells (HIV needs to get into another person's blood stream through mucous membranes (the tissue lining many body cavities and organs), direct injection, or cuts and sores).
5. A sufficient amount of organisms to establish infection (concentration of the virus in some body fluids is much less than others, which is why some body fluids are considered risky and others are not).

Studies show HIV is transmitted in three ways.

- **Sexual transmission**

HIV is spread most commonly by sexual contact with an infected partner. The virus can enter the body through the lining of the vagina, vulva, penis, rectum or mouth during unprotected sex, where semen, vaginal fluid or blood is exchanged between partners.

Having another sexually transmitted disease such as syphilis, genital herpes, donovanosis, chlamydia, gonorrhoea, trichomonas or bacterial vaginosis makes it easier for someone to become infected with HIV or for someone with HIV to pass it on to someone else. There are several reasons for this. All of these infections cause either sores or inflammation in the genitals. The sores caused by these STI's provide a way for the virus to enter the body. Wherever there are sores or any inflammation there will be lots of CD4 cells which are the target for HIV (in non-infected persons) or which are carrying HIV in them (in infected persons). In people who already are infected with HIV, there is more HIV in their semen and vaginal fluids when they have gonorrhoea or chlamydia.

- **Blood-to-blood transmission**

HIV is also spread through contact with infected blood. Prior to the screening of blood for evidence of HIV infection, HIV was transmitted through transfusions of contaminated blood or blood components. Today the risk of acquiring HIV from such transfusions is extremely small.

HIV is spread among injecting drug users (IDUs) by the sharing of needles or syringes contaminated with minute quantities of blood of someone infected with the virus.

HIV can be transmitted in traditional ceremonial practices that involve cutting and blood and where instruments are shared.

HIV can be transmitted in tattooing and body piercing or scarification where instruments are shared.

Transmission from patient to health care worker or vice-versa via accidental sticks with contaminated needles or other medical instruments is rare, but it has happened in Australia. It is important that health workers always take precautions. The book *Managing HIV* (Stewart 1997), published by the Australasian Medical Publishing Company includes guidelines for managing exposure to potentially contaminated body substances and recommendations for drug therapy after occupational exposure to HIV. Rather than reinvent the wheel, health services can either adapt or use this protocol. Details for obtaining this book are found in Appendix 5.

- **Mother-to-child transmission**

HIV can be transmitted from an infected mother to her foetus or child before, during or shortly after birth. Approximately one-quarter to one-third of all untreated pregnant women infected with HIV will pass the infection to their babies. If the drug Zidovudine (AZT) is taken by the mother during, and after, pregnancy, and by the newborn infant, the chance of transmitting HIV to the baby is reduced significantly. HIV can also be spread to babies through the breast milk of mothers infected with the virus. In Australia it should be possible to reduce mother to child transmission to about one to two per cent by using antiretroviral drugs and if the mother has a caesarean section before going into labour and does not breastfeed.

## **Viral load**

At certain times, people with HIV may have a higher concentration of the virus in their body fluids, ie. a higher viral load. This happens about one to two weeks after infection (lasting up to three months after infection) and towards the later stages of the disease when the immune system is severely affected. During these two stages the infected person is more infectious and there is a greater probability of them transmitting HIV through unsafe behaviours. However, it is possible for a person living with HIV to pass the infection on at any time after they are infected.

## **How is HIV not transmitted?**

There is no evidence to suggest HIV is transmitted by:

- saliva, sweat, tears, urine, or faeces;
- casual contact, shaking hands or hugging;
- by sharing eating utensils, bathrooms, toilets, telephones, money, used clothing or swimming pools; and
- when donating blood under sterile conditions;

- by vaccines or immune serum globulin;
- by biting insects such as mosquitoes or bedbugs;
- by sewerage and normal household waste; or
- when giving mouth to mouth resuscitation in an emergency.

## Who is at risk of contracting HIV?

Anyone who practices risky behaviours such as:

- unsafe sexual intercourse (vaginal or anal sex without condoms);
- sharing of drug injection equipment (ie. needles, syringes and tourniquets);
- oral sex (the risk increases if there are cuts or sores in the mouth);
- sharing of ceremonial cutting instruments between people in traditional practices.

## How can HIV transmission be prevented?

HIV transmission can be prevented by:

- proper use of good quality condoms for sexual intercourse;
- not sharing needles, syringes and other drug-injecting equipment;
- avoiding oral sex, especially by avoiding getting blood, semen or vaginal fluids in the mouth (the risk increases if the mouth has bleeding, cuts, ulcers or gum disease); and
- not reusing or sharing instruments in ceremonial practices.

## Living with HIV

Many people live for a long while before HIV related symptoms appear. Symptoms may not surface for a decade or more after HIV first enters the body in adults. However, children born with HIV infection can develop illnesses within the first years of their lives. Overall though, the period of "asymptomatic infection" (the period in which there are no symptoms of infection) is highly variable. Some people may begin to have symptoms within a few months. During the asymptomatic period, however, HIV is actively infecting and killing cells of the immune system. The virus initially disables or destroys CD4 cells without causing symptoms. All through this time, even if the person appears healthy, they are still able to pass the HIV on to others in the ways listed earlier.

Appropriate diagnosis of HIV can improve the quality and span of life of people with HIV. It gives them the opportunity to consider treatment, which can slow down the destruction of the immune system by HIV. The use of combination antiviral therapy has been shown to improve immune function, reduce the incidence of AIDS related illnesses and prolong life. This suggests that treatment can play a major role in maintaining the long-term health of people with HIV. The challenge is to identify and provide access to systems of care and support that will promote health and maintain quality of life for people living with HIV/AIDS.

## How is HIV diagnosed?

HIV is primarily detected by testing a person's blood for the presence of antibodies (disease fighting proteins) to the virus. HIV antibodies generally do not reach detectable levels until one to three months following infection (scientists are currently reviewing this time frame, it seems it could be shorter than three months).

People exposed to HIV should be tested for HIV infection as soon as they are likely to develop antibodies to the virus. Such early testing allows an infected person and their doctor to consider using antiretroviral treatment very early, at a time when it may have a greater impact. It is not yet known, but this may help people to live longer and healthier lives. It also allows the person to adopt a generally healthier lifestyle (cutting down drug use, eating better food etc) that will also help. Early testing also alerts HIV infected people to avoid high-risk behaviours that could spread HIV to others. It also allows them to reflect about the future; for example, if they have children they can consider plans for their family's future well being.

Two different types of antibody tests, ELISA and Western Blot, are used to diagnose HIV infection. The ELISA test is used first as the screening test. If the result is positive to HIV, or is unclear, the laboratory will re-test the blood with the ELISA test and with the Western Blot to be sure. If the person has only recently engaged in risky behaviour they may also be told to repeat antibody testing at a later date, when it is more likely that antibodies to HIV will have developed.

When the body begins to produce antibodies to HIV it is called seroconversion (the serum converts from HIV negative to HIV positive). About 80 per cent of those who get infected with HIV will experience an acute illness within the first few weeks. This is called seroconversion illness. Symptoms include fever and enlarged lymph glands and last about 14 days. It is often mistaken for glandular fever. People usually recover and are then symptom free for a long while. It is important that health workers ask the question, 'Could this be HIV?' when faced with symptoms similar to those of seroconversion illness (Stewart 1994).

## There is a difference between HIV and AIDS

AIDS stands for Acquired Immune Deficiency Syndrome. This is when the immune system is severely damaged and the person then develops a particular set of infections and malignancies. Some of these are opportunistic infections such as tuberculosis, pneumocystis carinii pneumonia and cryptococcal meningitis. Kaposi's Sarcoma is a common cancer.

In most cases HIV does become AIDS. However, if cared for properly, a person living with HIV can live for years before progressing to AIDS. Early treatment and health monitoring can potentially extend the period in which individuals remain well and are productive members of the community.

Much can be done to avoid some of the opportunistic infections or to manage them if they do develop. People with HIV and immune damage can take various prophylactic treatments.

## Hepatitis C

The following is taken from Hepatitis C: a review of Australia's response (Lowe and Cotton 1999)

All health care workers should be aware of the problem of hepatitis C. Approximately 200,000 Australians have become infected with hepatitis C. It is spread in ways that have some similarity to HIV transmission.

Hepatitis C has also become a serious health problem in Australia. The hepatitis C virus is primarily transmitted through blood-to-blood contact. Sharing of injecting equipment by drug users is the most common route of transmission and a single episode of sharing may result in infection. Sharing needles and syringes, tourniquets, spoons, water, filters and solvents may lead to transmission because small amounts of blood can be on any of them. (Lowe and Cotton 1999 p4)

Hepatitis C can also be transmitted during tattooing, and body piercing activities such as acupuncture, and ear piercing, if equipment is not sterile. It can also be transmitted in a health care setting from person-to-person exposure.

Sexual activity poses a very low risk of transmission, although it does seem that it can occur. There is a small (5 per cent) risk of transmission from a hepatitis C infected mother to her child.

Evidence exists that the virus can be transmitted through the sharing of razors and that there is some potential for transmission through sharing of combs or toothbrushes. There is a small risk of transmission through blood transfusion.

It is unusual to develop any serious illness at the time of infection with hepatitis C. Many people do not show symptoms and can remain healthy. Some people, at the time of infection, can have a flu-like illness. The major symptom is nausea, but extreme tiredness, abdominal and back pain, and headache can also be symptoms.

About 80 per cent of people exposed to the hepatitis C virus become chronically infected and are able to transmit the virus. For the majority of these people this infection is asymptomatic and will not progress to advanced liver disease. Of those with chronic hepatitis C infection, about 10 per cent may develop cirrhosis, usually by 20 years after infection. Some of those with Hepatitis C related cirrhosis will develop liver failure and others will develop liver cancer.

Health workers should become informed about hepatitis C and integrate education and treatment strategies into their services.

## References

Australian Federation of AIDS Organisations (AFAO) 1991, Safe Sex Guidelines, AFAO, Darlinghurst, NSW, pamphlet.

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## Chapter 2

### Confidentiality

A high level of sensitivity is attached to HIV/AIDS related information and the way this information is handled. More than many other diseases in history, HIV/AIDS carries a stigma, that seriously affects people with HIV/AIDS and those close to them. A lot of public fear about HIV/AIDS still exists in Australia. Such fear can result in social discrimination, isolation and unjustified persecution. Many people with HIV experience feelings of shame because of other people's attitudes. This makes it even harder for them to live with HIV. Confidentiality is essential for people living with HIV/AIDS.

It can be very easy to make a mistake about confidentiality, especially in a community setting. It is important to take time to think through how Indigenous health services can set up systems and protocols for maintaining privacy and confidentiality. This could include, staff in the health service being related to the clients and how records are kept and who sees them.

A lot of work has been done by mainstream HIV organisations to develop confidentiality guidelines and protocols. The Australian Federation of AIDS Organisations (AFAO) can provide guidelines for organisational policy, whilst State or Territory Health Departments should be able to provide local guidelines for health services and procedures.

These policies and protocols may not always meet the needs of Indigenous communities because of particular factors that have to be considered. This is why it is important that each Indigenous service takes the time to identify what confidentiality means for their organisation and community.

STD Control in Remote Aboriginal Communities: A Manual for Clinic Workers (DHAC 1999) has a useful section on privacy and confidentiality. It includes case studies, typical situations that can cause problems, and handy hints.

### What is confidentiality?

A confidential relationship is one where someone can be firmly trusted with information and can be relied upon to keep that trust. When someone is tested for HIV that person has a right to expect that any information about that test and its results are kept secret. This is also covered and reinforced by various codes of ethics, guidelines and laws. Of course, this applies to any health related information, not just to HIV/AIDS.

Confidentiality also applies to records and data collection.

### What is HIV related information?

HIV/AIDS related information is more than information to do with whether a person is infected with HIV or has AIDS. It also includes information about:

- whether a person is suspected of being infected with HIV or of having AIDS;
- information about any risk activities in which a person may engage (eg injecting drug use or sexual practices);
- information about sexual or injecting partners (whether a person has a positive or negative HIV test result); and even whether a person had a HIV test.



Information about a person's negative HIV test result that becomes public knowledge can cause as many negative or discriminatory reactions towards the person concerned as a positive result. The mere fact that someone has had a test may result in community members making assumptions about that person's lifestyle or HIV status.

## Why is confidentiality so important?

Confidentiality about HIV related information is very important for the following reasons.

- It is important to respect the rights and needs of people living with HIV/AIDS and to ensure that they are protected from intrusion into their personal lives.
- Confidentiality encourages people who may be at risk of HIV infection to be tested for HIV. This is essential in reducing the spread of HIV/AIDS in communities. Unless people feel safe about going to be tested for HIV they will not come forward. When a person knows they are infected with HIV then they can take care not to pass it on to someone else. Also, they can start to take treatments that may help them to live longer. Going for a test is also a good opportunity to educate people even if their result is negative.
- People with HIV or AIDS, and those close to them, can experience many problems and require assistance to understand this disease. It is important for them to have someone they can trust and to whom they can turn for help.

## What to include in confidentiality policies

The health worker and the Indigenous service must be able to send a clear message to people in the community that they can be trusted with very personal and difficult information. One very important way of doing this is to develop confidentiality policies.

The first step in developing confidentiality policies is to consult with the community to find out what confidentiality means to them. It is likely that this consultation will involve helping the community to understand the HIV epidemic. Across the world, when communities are dealing for the first time with the epidemic, people often say that they should be told who has HIV so that other members of the community can be protected. However, this approach is flawed because it can discourage people from being tested. The health worker and the service need to explain to members of the community the problems associated with this approach.

The second step is to explain to people in the community what confidentiality means to the service and how the service will protect people's privacy. This means that the service must have policies for protecting confidentiality and must train staff in how to follow those. Those policies could cover:

- when to collect HIV/AIDS related information;
- what a person should be told before this information is asked for;
- who in the service has access to records;
- how such information can be used or disclosed, apart from the original purpose for which it was obtained; and
- how HIV related information should be collected, stored and disseminated.

The way that information about HIV is stored is very important to keeping HIV information confidential. Usually health clinics create a coding system for HIV testing. This means that all that is recorded in a person's file is that they had a test and that the result was given. The actual result is listed under a code in another file; the person's name is not on this. This file is

locked away and only certain workers can access it and know how to interpret the codes. Policies should be consistent with the procedures listed in chapter 3, where a client is given an explanation of the procedures that will apply to their blood test.

There is a legal and ethical obligation to keep all patient information confidential, but protecting information about HIV is particularly important in view of the social stigma of AIDS. This can become even more complex in community organisations such as health centres. Staff members can know, or be related to, patients. For this reason, organisations need to develop confidentiality policies that suit local circumstances.

Formal procedures for protecting the release of HIV related information from health services, clinics, hospitals and general practices need to be developed. These procedures should also cover the release of information for research and to the media. Instances of breaches of confidentiality have been reported. All staff should be aware of, and follow, the organisation's policies on confidentiality. New staff should have these policies explained to them.

Strategies for developing policies are found in chapter 7.

## Legislative requirements

There are a number of legal requirements to do with the handling of sensitive medical and personal information that Health services need to be aware of. These are addressed in chapter 4.

A breach of confidence by a medical practitioner may constitute professional misconduct under relevant legislation regulating the medical profession and other health professionals in each State and Territory.

### More information

More information is available from the following sources.

Contact Tracing Manual: A Practical Handbook for Health Care Providers Managing People with HIV, Viral Hepatitis, Other STI's and HIV-related Tuberculosis 1997, DHFS, Canberra.

Department of Health and Aged Care (DHAC), Office of Aboriginal and Torres Strait Islander Health 1999, STD Control in Remote Aboriginal Communities: A Manual for Clinic Workers, DHAC, Canberra.

Intergovernmental Committee on AIDS 1991, Legislative Approaches to Public Health Control of HIV Infection, Legal Working Party Discussion Papers, AGPS, Canberra.



## Chapter 3

### HIV information, testing and counselling

This section has guidelines and steps for providing information, HIV testing and counselling when dealing with people who may be infected or affected by HIV/AIDS. The following topics will be covered in this section:

- issues around HIV antibody testing;
- pre-HIV antibody test information;
- post-HIV antibody test information and counselling; and
- treatment and ongoing counselling and support.

### Counselling in Indigenous contexts

Approaches to counselling are likely to vary from one Indigenous community to another, and between social groups in those communities. The availability of resources, the conventional or traditional ways in which illness is understood, and the ways in which advice and help are sought and provided will all influence the pattern and techniques of counselling (Skov 1996). The characteristics of the person and his or her social and family networks will also influence the extent to which counselling is needed (Campbell & Rader 1995).

Health workers can be concerned about how to provide HIV tests and counselling. Reasons for this can vary: in some remote communities language barriers can make it difficult to get informed consent or some workers may worry about the ability of the health service and the community to cope with a positive test result or feel that they don't have the training and skills to provide this service confidently (Skov et al. 1996).

As there have only been fairly small numbers of HIV infections among Indigenous people there is not yet a lot of experience to draw from to develop a better understanding of Indigenous HIV counselling procedures. However, some services have addressed this issue quite well.

Counselling in Indigenous communities will often extend from the individual to the family and the community. The notion of community is important to Indigenous people and the needs of the community will affect how services are provided. However, the community's needs should not undermine the right to confidentiality for individuals (Campbell & Rader 1995).

### Drawing on experience

Indigenous communities have a wealth of experience to draw from when discussing how HIV will affect them. Their experience in survival to date, and ongoing decision making around issues such as land, law, environmental health, funding submissions and royalty money demonstrates their abilities to ensure good outcomes for individuals. This has involved placing importance on sharing information and facilitating a spiritual counselling process that integrates individual rights with public responsibility. These experiences can be used to deal with HIV in the most appropriate way for individuals, families and communities (Campbell & Rader 1995).

The personal impact of being diagnosed with HIV should also be seen against the framework of the overall disintegration of traditional Indigenous culture, and the disruption of tribal authority structures and family life. In this context, for someone suffering from the shame of HIV, the

potential for self-harm from behaviours such as alcohol and drug abuse and suicidal tendencies is increased. These possibilities should be taken seriously in planning and developing services and must be an important consideration in individual casework. Health services can assist staff to address counselling issues by developing tools which help people share accurate information, absorb loss and grief, create hope, and maintain strong spiritual links with people's sense of self, their family, and their culture (Campbell & Rader 1995).

## Testing for HIV - background information

Every person who asks for, or is offered, a HIV test must be offered information about the consequences of the outcome. This is because the issues involved in having a HIV test can have serious outcomes for the person involved. It is important that the person has the chance to think about those consequences, and be as well prepared as possible for the results. Furthermore, the result of a HIV test is not only very important for the person involved, but also has implications for that person's partners, family and community.

Pre-test information is an important part of the counselling process. It can help someone prepare for a positive HIV result. In many cases, it may be the only opportunity for counselling support, as on hearing a positive result some people will not want further counselling and may not return for it (Begley 1991). Pre-test information is also an educational opportunity for people, regardless of whether they will have a positive or a negative result. It provides a chance to talk about any risk behaviours they have and to look at ways to change or avoid them in future. Often people come for a HIV test because they have done something that has caused them to worry about the possibility of HIV infection.

## What is the HIV test?

The HIV test looks for antibodies to the Human Immunodeficiency Virus (HIV). These are the antibodies in the blood that have been formed by the immune system against the HIV. This test does not look for the virus itself.

There are two different types of test, enzyme-linked immunosorbent assay (ELISA) or Western Blot. Both tests can detect HIV antibodies. The initial screening test is commonly done using the ELISA test. These tests can detect antibodies from about two weeks after infection (Stewart 1994).

If the result is positive or unclear, the same blood is tested again with both the ELISA test and the Western Blot test to make certain of the result. A positive result means that the person is infected with HIV.

A negative result means that HIV antibodies were not found in the blood sample. Often this means that the person does not have HIV. However a negative result does not always prove that the person is not infected with HIV. The person could be in the "window period", having had unsafe behaviour so recently that the antibodies have not yet been produced in the blood. In these cases the person needs to be tested again, usually three months after the risk behaviour (ie. three months from when they last had unprotected sex or shared injecting equipment).

## When should you offer a HIV test?

A person should be offered a HIV test (Nganampa Health Council 1997):

- when they request it;
- if they have, or recently have had, an illness that might be connected with HIV primary infection (seroconversion illness).
- if you think they have an illness that might be a HIV or AIDS opportunistic symptom;
- if they have an STI;
- if they have had unsafe sex with a person with an STI;
- as part of an antenatal check-up;
- if they have ever shared needles, syringes or other injecting equipment when injecting drugs;
- if they have had unsafe sex with a person who has shared injecting equipment; or
- if they have taken part in ceremonial practices involving blood letting and are concerned about possible transmission through shared instruments.

## Steps for providing a HIV test

### Confidentiality

Explain the health services confidentiality procedures, informing the person that:

- their name will not be put on the form or on the blood sample;
- the person taking the blood will not tell anyone that they have been tested;
- their name will not be on the test results - results are coded (some medical services put results into a special folder in the clinic - results are not put in patients notes); and
- they will be told in person about their results and no-one else will be told.

Explain the notification procedures in that State or Territory.

The topic of confidentiality is also covered in chapter 2

## Informed consent and the HIV test

Pre-test information ensures that people are able to make an informed decision about going ahead with the HIV test. The pre-test information should cover the medical details, and the possible effects of a HIV diagnosis on their emotions, relationships, work, community and future. This should include informing them that a HIV diagnosis can affect superannuation, life insurance, and possibly have implications for work and employment.

A person has the right not to proceed with a test.

## Topics to be covered in HIV test information

The number of issues to cover when providing HIV test information might seem overwhelming. As a health worker you might feel that you may not be able to do this well. However, the task will be less overwhelming if you prepare and if you use the checklists. The most important first step is to get the client's trust.

The health worker will need to ensure that the client:

- understands, and has given, informed consent for the test and pre-test information;
- knows that it is not possible to tell if they have HIV just by looking at them (you can only tell by giving them a blood test);
- knows that the test will involve them giving a blood sample;
- knows this test looks for HIV anti-bodies in their blood;
- knows the steps taken to ensure confidentiality and privacy about them and the results;
- has been given information on how long it will take to get the test results and understands that they must come back to get the result;
- understands that a person can get infected by HIV and some other STI's at the same time, and in the same way;
- has answered Personal Risk Assessment questions (see next heading);
- understands about safer practices to reduce the risk of getting HIV or an STI (ie. using condoms or dental dams during sex; using their own clean needle, syringe and other equipment when injecting drugs; and knows that alcohol and drugs can reduce personal control over safe behaviours in risky situations);
- understands that HIV can be transmitted from mother to child before, during and after childbirth;
- understands that they will probably become anxious while waiting for the test results to return and has talked about some ways of coping with the pressure; and
- if appropriate, has made an appointment to return for the results.

Sometimes showing a video about HIV can help people to understand more. Local Indigenous sexual health workers should have videos and other educational resources.

Some health services in Central Australia have produced short (5-7 minute) audio tapes and video tapes which provide pre-test information in the person's first language. Separate tapes have been produced for men and women. These resources were developed to fit local contexts and needs.

The following sections give more information that the health worker will require to provide testing and counselling.

## Information and procedures for health workers

### Personal Risk Assessment

Health workers should not make decisions based on the appearance of the person, or based on assumptions about their sexual or drug injecting behaviour. Details about a person's private behaviour will only be properly known when that person states it. This will usually occur when the person feels they can trust both the health worker and the service with this information. In particular, people will reveal this information if they believe the health worker will not make judgments about their behaviour and identity.

The health worker should conduct a Personal Risk Assessment as part of the HIV pre-test information. This helps to identify what risks the person has for getting infected with HIV or STI's. Answers to these questions are important. This is where the health worker needs the trust of the client. It can be difficult to ask and answer these questions. It may help to explain that by asking these questions it is possible to work out what their risk of HIV is.

A Personal Risk Assessment should cover the following:

- Have they or a partner, now or in the past, had an STI or symptoms of an STI?
- Have they or their partner, now or in the past, had other partners (same sex or other sex)?
- Have they, now or in the past, used condoms?
- Have they, now or in the past, used/shared needles?
- Do they think they need a HIV test?



These questions provide the opportunity for open discussion about people's behaviour and history. Each question allows for further discussion about issues specific for that person. For example, the question about condom usage should be drawn out to explore when condoms might or might not have been used.

## Five conditions for transmission of HIV

To explain HIV transmission to clients it may help to use the list of conditions needed for transmission. This list is found at the beginning of chapter 1.

## What is the "window period"?

The window period is the time between infection and the moment when the HIV antibody test becomes positive (Stewart 1994). The HIV antibody test will usually begin to detect antibodies from between two weeks to three months after infection. The time varies from person to person because the time taken for antibodies to show up in a person's blood can vary. This time is called the "window period" and is considered to apply for three months.

For practical purposes, if the result is negative three months after the client's exposure or risk behaviour, infection has probably not occurred (Stewart 1994).

The important thing is to get a clear explanation, and the date, from the client about when they last engaged in risky behaviour. This date is used to work out when the three-month window period would finish. If the first test is done within the window period then it would be sensible to conduct another test at the end of the three months. If the client has unsafe behaviour during this time then the process goes back to the beginning. The client could have become infected at that last contact so the three-month window period must start again from that date.

If the client has been tested within the window period it is important that they understand that, even if the test result came back negative, there is still the chance they are infected. They should not think that they are uninfected until they are tested the second time and get a negative result.

## Illnesses that might be HIV infection

When a person has HIV they will often have the same kinds of illnesses as people who do not have HIV. Therefore, health workers need to be aware of HIV related illnesses and consider the possibility that people may be infected with HIV but not be aware of this. If a client seems to have HIV related illnesses the health worker should talk with them about having a HIV test and explain why there are concerns.

### Seroconversion illness

About two to six weeks after infection about 50-70 per cent of people will have a seroconversion illness (Stewart 1994). The seroconversion illness lasts for one to two weeks and is usually a significant illness, somewhat like glandular fever. The main symptoms are:

- sudden onset of fever, headache, sore throat, lethargy, aches and pains, night sweats;
- raised lymph nodes (especially head, neck and armpits);
- rash;
- sometimes small round ulcers in the mouth, on genitals, or around the anus, or numbness, tingling or weakness in arms or legs.

## HIV related illness

A HIV related illness may be any infection which looks unusual, is worse than usual, lasts longer than usual, doesn't get better with usual treatment or keeps coming back, including:

- oral thrush in children and adults;
- herpes simplex infections (oral or genital) if very severe or occurring regularly;
- shingles (herpes zoster);
- molluscum contagiosum - small (2-3mm) clear or pinkish lumps on the skin that have a depression in their middle;
- new skin rashes that are hard to treat, especially seborrheic dermatitis;
- painless, striated white patches on the side of the tongue (oral hairy leukoplakia);
- chronic diarrhoea in an adult for more than one month ;
- chronic weight loss in an adult;
- night sweats or fevers lasting more than one month;
- generalised lymphadenopathy, ie. any disease of the lymph;
- Kaposi's Sarcoma;
- tuberculosis;
- low white blood cells or platelets; and
- any neurological symptoms.

## Doing a HIV test

Ideally the same health worker who takes the blood should do the pre- and post-test counselling. This way the health worker understands the client and will be able to assist them to cope with the results. However, in some remote area (traditional) communities it may be an advantage to have the doctor take blood and the health worker do the information sharing. This helps shift the blame from the health worker if the diagnosis is positive.

If possible, female workers should see the women and male workers see the men. It is not recommended that a person be counselled about their HIV status or sexual behaviour with other people present. Also if a separate room is used, it is better if it is used for other purposes as well so it is not labelled 'the AIDS room'.

The health worker should make sure they have the following:

- a private room which can be locked;
- sufficient time;
- pre-test information checklist (see this section);
- condoms and a penile model and other appropriate education resources to demonstrate safe behaviours; and
- equipment for performing the test, namely
  - pathology request forms
  - gloves
  - sharps container
  - tourniquet
  - swabs
  - needles
  - blood tubes
  - vacutainer holder.

Ideally, this equipment should be in both the women's and the men's rooms so you do not need to walk in and out of rooms to get what you need.

These guidelines are taken from Miller (1994).

## HIV Pre-test information check list

Health workers can use this list to check that all relevant details have been covered in the discussion with their client.

1. What the test is for?
2. What is HIV/AIDS?
3. Personal Risk Assessment.
4. Confidentiality.
5. What a negative result means.
6. What a positive result means.
7. What a positive result would mean to them - whom they would tell, who could support them.
8. Discuss safer sex (or no sex until results are known) and safe injecting practices.
9. Offer condoms.
10. Informed consent given and documented.
11. When to return for results.

## Post-test counselling

Whatever the result, negative or positive, each person needs to be properly counselled after the test. This is especially relevant if the person had asked for the test because they were concerned about risk behaviour. Even if their result is negative this is another chance to talk with them about their worries and how they might change their behaviour to avoid risking infection in the future.

Before seeing the client it is useful for the health worker to spend some time planning the upcoming session, thinking about the issues that could arise and possible approaches to handle them.

The following information has been adapted from an information manual developed by the Nganampa Health Council for clinic doctors and nurses on the Anangu Pitjantjatjara Lands (Miller 1994).

## Giving a negative result

Talking about transmission of STI's and HIV is still very important after giving your client a negative result. Some people may feel that now it's okay not to be careful about what they do in risky situations. The health worker can reinforce that the person is lucky not to be infected at this time, but that HIV is real. The health worker should make sure the client understands how to prevent getting infected.

Usually information about HIV transmission is not enough to change people's behaviour. People need to look at the reasons why they get themselves into risky situations. This can be complex. People have many reasons for having sex or using drugs. This is why it is often important to have broader education campaigns that encourage whole community understanding about risk behaviours and to get them to talk more openly about what behaviour needs to change. This may require setting up a supportive program to help them with behaviour change.

The following steps give a guide to the procedures involved when counselling a person with a HIV negative result.

- Use a quiet space where you will not be interrupted.
- Reinforce the confidentiality aspect of the consultation.
- Talk about how this information will be stored.
- State the result simply.
- Explain the result and whether they need a retest if there is doubt about the window period.
- Take the opportunity for education about reducing future risk. Talk about alcohol and other drug use, and unsafe sex and injecting (offer resource material, condoms, needles etc).
- Try to answer any questions the client may have. If you cannot answer all questions ask for help.

## Giving a positive result

It is traumatic for health workers to have to inform a client they are infected with HIV. The health worker's agency should ensure that they have been adequately trained to 'break bad news'. The organisation should also establish procedures to help the worker prepare, including having someone to talk with beforehand. This could be a colleague or a worker in another agency such as an STI clinic.

It is important that a health service should have already thought through how it will handle giving a positive test result. In chapter 7 this manual considers how organisations can develop appropriate policies and procedures.

The following steps provide a guide to the procedures necessary when counselling or talking with a person with a HIV positive result. However, it is likely that many of the topics cannot be properly discussed at the same appointment when a person is told their diagnosis. As the client will probably be shocked, and unable to concentrate, the focus should be upon how they will manage in the next few days. The shock that people experience can also become denial. Also, people often feel that it is a death sentence, despite the information about likely life span and reasonable health. Because of this the health worker can concentrate on the following topics with others to be covered in later sessions. Giving them information to read later can help. Above all, it is important that the health worker reassure the client and encourage them to return in a few days for further information and support.

The key considerations are:

- Use a quiet space where you will not be interrupted.
- Reinforce confidentiality aspects of the consultation.
- Talk about how this information will be stored.
- State the result simply.
- Explain the result. Focus on explaining that this means they have HIV. Check they understand the difference between HIV and AIDS. Get them to describe their understanding of the result and correct any misunderstanding.
- Tell them about treatments and encourage them to be hopeful.
- Try to work out their emotional response. Emotional reactions may vary from person to person: most people are shocked by a HIV diagnosis, some can disguise this.
- Ask who they want to know about the result. Sometimes if people do not identify someone that they can trust and talk to they might find that in coming days they become distressed and tell the wrong people, risking a bad reaction.
- If they have a partner, discuss what they want to do about telling them.
- Take blood so the test can be repeated and to obtain a measure of CD4 count and viral load.
- Make another time to meet (preferably as soon as possible).

A person who has just been diagnosed with HIV should be offered long-term support. Even if they say no to such support, it is important for them to know it is there if they want it later on.

From this point the health worker should be looking at other services that can become involved in giving support and information. The range of these is discussed in chapter 6.

At the next appointments look at the following.

- Establish local support.
- Refer to support groups/networks.
- Talk about medical follow-up. Discuss treatment options, including viral load testing and combination antiretroviral therapy (it is best to have baseline information on CD4 count and viral load available before making decisions on treatment).
- Provide information and resources for safe practices (safe sex, safe needle and syringe use).
- Discuss the client's plans for the next 12 to 24 months and how having HIV might affect them.
- Discuss prevention of further transmission and the need for partner notification/contact tracing.

Contact tracing is an important and sensitive issue as it traces other people who may have been exposed to infection and do not know it. It is addressed in chapter 5.

## Reactions

How a client reacts to news of HIV infection will depend not only on the individual's social supports, but also on how they have coped with previous major stresses. A brief history of previous coping mechanisms will alert the health worker to possible areas of difficulty.

The following table highlights some possible psychological responses to HIV infection. It is not a complete account of possible reactions but shows a variety of reactions people may have.

Possible Reactions	Possible Psychological Responses
Shock	Expressed as numbness, feeling faint, disinterest, distress or non-concern. Emotional shut down.
Anger	Blame, guilt, suicidal expression, violence, and physical abuse.
Anxiety	Who will know, who to tell, withdrawal. Due to the shock, some people will tell everybody, causing potential social problems such as loss of family, friends, job etc.
Fear	Death sentence, life sentence
Denial	It's not true, the laboratory is wrong, you're wrong. I'm not sick. How could this be?

Adapted from the Peninsula and Torres Strait Primary Care Manual, n.d.

## Ongoing counselling and treatment for people with HIV/AIDS

### Information on HIV treatments and viral load

HIV is active from the moment of infection and causes progressive damage to the immune system. Because of this, any decision about treatment should be made as early as possible after the diagnosis of HIV infection. As well as invading CD4 cells, the virus can attack other cells. For example, it can attack the brain and impair the way the brain works, causing dementia. It can also attack the gut and cause weight loss (wasting).

#### Antiretroviral drugs

People with HIV/AIDS can take a number of medications that attack the HIV virus and maintain immune function. These medications are called antiretroviral drugs. However, they are not a cure for HIV or AIDS.

Research has shown that taking a combination of these antiretroviral drugs is better than just taking one. People often call this 'combination antiretroviral therapy'.

These drugs slow the reproduction of HIV by entering infected CD4 cells and interfering with the way the virus reproduces. This helps to protect uninfected cells. Taking these drugs means there will be fewer viruses attacking uninfected CD4 cells and more healthy cells to fight infection. This improves the chance that people with HIV/AIDS can stay healthy for longer.

These effects can be measured by observing changes in the viral load. This is the amount of virus in the body. Shortly after infection with HIV, the virus starts replicating rapidly and there is a dramatic increase in the amount of viral load. Then the immune system responds and makes the viral load fall. During this period, which can last many years, people rarely have any symptoms. But the virus is always active and gradually the viral load increases again. This increase is a sign that the disease is progressing. The CD4 count begins to fall and the person is at risk of developing opportunistic infections.

When a person living with HIV/AIDS is using antiretroviral drugs they regularly have a blood test to monitor their viral load. This lets doctors monitor the use of antiretroviral drugs to keep viral loads as low as possible.

Treatment strategies use two or more of the following classes of antiretroviral drugs in combination therapy.

- Nucleoside reverse transcriptase inhibitors.
- Protease inhibitors.
- Non-nucleoside reverse transcriptase inhibitors.

#### Adherence

People living with HIV/AIDS need to take these drugs at specific times every day. Many people find it difficult to adhere with these protocols. This problem with 'adherence' has become very significant. The benefits of the drugs depend upon people taking them in the correct dose at set times during the day. If people can not follow these instructions there are concerns that the virus will continue to reproduce within their body and thus the drugs will not have benefits. There is a wider concern that this may cause the virus to mutate and develop drug resistance. This could complicate the value of these drugs in the future for other people. The health worker will need to be aware of this when working with a client, particularly as poor adherence to prescribed treatment is a well-recognised problem in communities where people have inadequate housing and mobile lifestyles. Some combinations are better than others for people who have trouble with adherence; for example, only taken twice a day rather than three times, or taken with or without food compared to those that must be taken half an hour before eating.

Many of these drugs have side effects that have to be monitored. Often clients need to alter the combination of drugs they are taking.

Unfortunately these antiretrovirals do not work for everyone with HIV/AIDS. Some people's immune systems are already too damaged and the drugs are not effective. For other people the side effects of the drugs are severe and they stop taking them.

Decisions about taking antiretrovirals need to be made in consultation with a doctor who specialises in HIV medicine and is able to prescribe them (see glossary).

There are always new developments with drugs and drug trials. Indigenous people particularly those in remote areas, need equal access to information and ability to benefit from them.

Further information can be obtained from the Treatments Information Project at the Australian Federation of AIDS Organisations. Contact details are in appendix 4.

## Short-term counselling needs

In the first weeks and months after a person is diagnosed with HIV a number of issues will be important.

- Health implications. Explore the level of understanding people have about their health and what having HIV does and does not mean.
- Deciding who should be told and why.
- Building a support network.
- Having peer support from others living with HIV/AIDS.
- Ongoing education about living with HIV.
- Deciding about treatments, taking them properly and coping with side effects.
- Exploring how to still feel good about sex.
- Getting referrals to specialist services such as counselling, accommodation, social security.

There can be additional issues for Aboriginal and Torres Strait people who are gay or transgender (sistagirls). They include:

- Marginalisation and cultural stigma within their own communities.
- Generational poverty contributing to social disadvantage.
- Cultural alienation.
- Broad scale vilification.
- Sexual abuse.
- Fear of denial concerning individual identity.
- Inhibition of individual sexual identity and expression.

## Long-term counselling issues

People with HIV/AIDS will have many ongoing counselling needs. The kinds of issues that come up for them will vary depending on the stage of their illness and how it affects their lives.

The participants at the workshop responsible for designing this manual saw the following issues as important over the long term for Indigenous people living with HIV/AIDS.

- Grief and loss. This can have many aspects: the loss of friends, the loss of lifestyle, the loss of health.
- Other social issues such as multiple deaths, and other diseases prevalent in Indigenous communities, including diabetes and heart disease.



- People infected through heterosexual contact may find they are being associated with “gays” and “drug-users”.
- Drug and alcohol use or misuse.
- Monitoring the psychological effects of HIV treatments.
- Fear of discrimination and rejection.
- Worries about dying on someone else's land.
- Planning burial rites.
- Support needed outside of normal working hours.
- Wanting to go home, or having to move from home so their families do not experience discrimination.
- Changing roles in their personal relationships, such as going from being the carer or provider to being cared for.

## Counselling from afar

Some clients will have to travel away from their home to get good care and support. This may be permanent or temporary. They need support with acquiring skills and resources to live away from home. They may need the following to be organised.

- A referral/support network that will help them in the place they are going to. The case management of this could involve making sure someone will meet them, making contact with agencies before they go, arranging accommodation, and booking welfare and medical appointments. It may be useful for them to have an information and contacts sheet to take with them when they travel.
- Assist the family, friends or other affected people to remain in touch with the person who has travelled away so that care and support works are maintained.

## Recalcitrant behaviour

Recalcitrant behaviour is where people who have HIV knowingly put other people at risk of HIV infection. People in these circumstances may need to be offered regular reviews and counselling, education and help with behaviour change and, in some instances, they may need to be isolated in the interests of public safety. Each State and Territory has laws about this. See chapter 4 for further information.

## The end phase

When AIDS has progressed to a point where a client is likely to die soon, steps can be taken which enhance the quality of the last part of life. As in all other phases of AIDS related illness, dignity and choice are the most important elements to maintain.

The person who has reached the final stages of AIDS may wish to consider a number of issues. The role a counsellor plays here in raising these issues is a very difficult and challenging one. How a client reacts may depend on the strength of the relationship with the counsellor. Their reaction can also be affected by their health at the time and how they are feeling.

Some issues that could be considered are listed below.

- Where does the client wish to die?
- Who do they want with them during the last part of their life?

- What palliative care or pain control methods will be available? What affect will they have on the dying process? Can they cause death? What are the options?
- Will the medical treatment affect the quality of their final days? What are the options for drug treatment? Who is the best person to advise on this?

An individual should have the option of addressing these questions before they arise so that their choices are honoured. The advice of additional specialists or organisations may be needed to answer questions about dying.

Some people may choose not to address these questions until later, or they may choose to die without extra preparation.

Whatever the choice, carers and others will need to ensure that the time, space, and other resources are available to meet, where possible, the wishes of people living with HIV/AIDS. At the request of the individual, carers may need to contact relatives or friends to allow them to respond to their wishes.

In working with a client through this emotional phase, a counsellor will need to be prepared with strategies to offer to help facilitate this process. Local AIDS Councils can provide resources on preparing for death as well as information about services that can assist. Their contact details are in appendix 4.

### Important issues to consider

- Traditionally, the issues and cultural factors affecting men are different from those affecting women. The needs of Indigenous people with HIV/AIDS should be defined in terms of men's health business and women's health business (not 'law business'), particularly in the more traditional/remote communities - although this also has urban relevance.
- Special consideration needs to be given to the impact of a HIV positive diagnosis for people maintaining a traditional way of life. Find out about their cultural beliefs and practices. Do not assume it will be the same for everyone.
- Some Indigenous people in rural and remote areas have very mobile lifestyles. This can make ongoing counselling and medical follow up difficult. Individuals with mobile lifestyles may need to know how they can access services regardless of where they live.
- Confidentiality around HIV/AIDS helps the person living with HIV/AIDS to control some of the negative social impacts of the disease. The critical issue is letting them decide who should be told about their diagnosis and why and how this should happen. The aim should be to minimise the risk of rejection and to maximise social supports, especially by using existing supports such as partners, family and community.
- The partner, family and friends of the person living with HIV/AIDS may also need some support. They can also experience shock, denial, anger, and depression and this may affect their ability to care for the person living with HIV. Often the needs of those affected by HIV/AIDS are overlooked or underestimated, but they can be profound. Providing support assists them to give better support to the person living with HIV/AIDS.
- Mental health is a crucial issue for those affected by HIV/AIDS. Depression and anxiety are common among people with HIV/AIDS, and these can sometimes develop into a psychiatric disorder. Harmful behaviours such as alcohol and drug misuse can be a problem, as can suicidal thoughts and wishes. The health worker must be aware of these possibilities. Monitoring mental health should be an essential part of ongoing work with the patient. This should be included as a core part of the planning and development of HIV services.
- Providing long-term counselling to an Indigenous person living with HIV/AIDS will require an understanding of the impact on the individual of the overall disintegration of traditional Indigenous culture, and the disruption of traditional authority structures and Indigenous family life.
- It is important that the counsellor is acceptable to the person and the community. This may mean that the counsellor is Indigenous, although this is not always essential. The use of local language has specific importance for explaining information about sexual health and HIV/AIDS education. The counsellor will need to understand these to be effective.

- In talking about traditional ceremonial practices it is important to acknowledge that there are special concerns about blood letting. Counsellors should know that it is not usually appropriate to discuss the specifics of ceremonial practices openly. Gender separate practices should not normally be discussed with members of the opposite gender and, in Aboriginal culture, initiation is not normally discussed with the uninitiated - men's business', women's business' and 'law business' are acceptable euphemisms for initiation ceremonies.

## Addressing stress experienced by workers

It is important for employers and organisations to appreciate the stress that counsellors go through and to provide appropriate support. These counsellors should have individual debriefing and support. Culturally appropriate debriefing may have to be done outside of the organisation. The counsellor should be consulted about the best way to support them in their work. Workers in this area are subject to high stress and frequent physical and emotional fatigue. Steps to prevent 'burnout' are essential.

Counsellors working in small communities may find getting support is especially complicated. Their colleagues may have connections with the patient so confidentiality prevents the counsellor being able to discuss the case. Perhaps there is no one locally with the capacity or experience to assist the counsellor with advice or supervision, especially for complex cases. In these instances it is important that established procedures exist for the counsellor to get support from elsewhere. If such support is not available, their capacity to do their job properly is in jeopardy.

Counsellors need to access training in order to be effective. Indigenous counsellors need access to ongoing professional development and training to achieve better outcomes for all and to develop relevant skills to work with people living with HIV/AIDS. In the long term this may mean identifying the ways that Indigenous people can work most effectively, and being flexible enough to address individual circumstances.

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## Chapter 4

### Legal issues

The Third National HIV/AIDS Strategy insists that a supportive legislative environment is essential for responding to the HIV epidemic. This strategy gives six guiding principles that should be reflected in public health measures:

- Principles of access, equity, participation and equality for individuals, a client focus, and a supportive legislative environment are integral to Australia's success in responding to HIV/AIDS and related communicable diseases, notably hepatitis C.
- People living with HIV/AIDS, and those with other chronic diseases, have the same rights to accessible, quality and confidential legal information and advice as other members of the community, without fear of discrimination.
- Law reform should take a rational, human and responsive approach to the significant issues that are presented by HIV/AIDS and related communicable diseases.
- Laws specific to HIV/AIDS alone require particular justification.
- Reform measures should be as uniform as possible across jurisdictions.
- Policies designed to eliminate continuing patterns of discrimination and to reduce prejudice and violence directed against homosexual or transgender people, people living with HIV/AIDS or hepatitis C and injecting drug users should be promoted by all governments.

Much work remains to be done in both non-Indigenous and Indigenous community controlled primary health care organisations to ensure that people are not discouraged from seeking treatment, advice, care and support for HIV infections. Reducing discrimination is a complex task. Four policies have been identified in the Indigenous Sexual Health Strategy to meet the needs of those most affected.

- Adopt service policies that do not discriminate against gay men and lesbians.
- Pursue rigorous policies to protect the confidentiality of client information.
- Take a harm minimisation approach to injecting drug users.
- Ensure groups at risk of discrimination are represented on health service boards.

### Legal issues that may arise

A wide range of legal issues can apply to health workers. The following list gives an overview of the key topics. Each State and Territory has legislation which impacts on the duties of health care professionals. Further, each State and Territory has legislation which provides for notification of a range of infectious diseases, including HIV. Health workers should ensure that they are familiar with the legislation that applies in the area where they provide services.

### Guarantees of confidentiality

Health care professionals are bound by a common law duty of confidentiality. In addition, some States and Territories provide added statutory guarantees of confidentiality about HIV status.

## Notifying infections

In all Australian States and Territories HIV infection is notifiable to government health authorities. There are differences in notification requirements between the States and Territories. Once HIV infection is notified, the relevant State department of health can assist with issues such as partner notification and dealing with those whose behaviours place others at risk.

## Safe sex and partner notification

In some States it is a requirement that a person living with HIV must inform sexual or drug injecting partners.

## Duties to third parties

So far in Australia, there have been no legal precedents that require health care professionals to inform sexual partners of people with HIV of the risk of infection. It is possible that fear of litigation may play a part, following publicity surrounding the Tarasoff decision and subsequent decisions in the US.

## Powers of attorney

A power of attorney is a legal document which appoints one person (the attorney) to act on behalf of another (the principal or donor) in the areas of property and financial management. The attorney is usually a family member or close friend, and does not have to be a lawyer or solicitor. A power of attorney does not enable a person to make medical or life decisions on behalf of another. An ordinary power of attorney ceases to have effect when a person ceases to have mental capacity, while an enduring power of attorney continues after such a time. A person living with HIV may face some form of mental incapacity or dementia later in their illness. That person may wish to consider making an enduring power of attorney while they are of sound mind, so that the slow and expensive process of appointing a financial and property manager can be avoided.

## State and Territory legislation

Legislation dealing with HIV/AIDS and procedures for reporting and managing HIV/AIDS and HIV related offenses differs in each State and Territory jurisdiction. For information on State and Territory legislation, the Australian National Council on AIDS and Related Diseases (ANCARD) has produced Status Report on implementation of the final report recommendations of the legal working party (June 1999). This document reviews the jurisdictional differences in selected HIV/AIDS legislation.

Over time laws are changed or altered. For the latest information on current legislation in each State or Territory, health workers should contact their relevant health department for explanations and interpretations of the laws.

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## Commonwealth Disability Discrimination Act

Specific Commonwealth legislation dealing with disability discrimination addresses discrimination regarding HIV. The Commonwealth's Disability Discrimination Act (DDA) protects persons with a disability from discrimination. In other words, it is unlawful under that Act to treat a person with a disability less favourably than a person who does not have such a disability.

The Disability Discrimination Act includes the following categories of disability.

- Physical
- Intellectual
- Psychiatric
- Sensory
- Neurological
- Learning
- Physical disfigurement
- Disease-causing organisms present in the body.

This broad definition is meant to ensure that everyone with a disability is protected.

The DDA covers a disability which people:

- have now;
- had in the past (eg a past episode of mental illness);
- may have in the future (eg a family history of a disability which a person may also develop);
- are believed to have (eg if people think someone is living with HIV/AIDS).

The Act imposes penalties on persons who discriminate on the basis of a person's disability. Orders made under the DDA by the Human Rights and Equal Opportunity Commission can be enforced by the Federal Court.

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## Further information

Community Legal Centres or Aboriginal Legal Services have qualified legal practitioners on hand to answer questions or refer people to appropriate places, although they may not have had much experience with handling HIV related cases. Some of the larger AIDS Councils have HIV legal services. All AIDS Councils can assist with advice and referral. The AIDS Councils are the best places to give information or referral to specialist legal advice.

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## Publications on legal matters

HIV/AIDS Legal Link is a quarterly journal published by AFAO which covers the latest developments in HIV/AIDS law and policy around Australia and in the Asia-Pacific, including developments related to discrimination and human rights, confidentiality, public health laws, insurance and superannuation. This is a specialist publication, more suitable for legal workers (see appendix 4 for more information).



## Chapter 5

### Contact tracing and partner notification

The following is adapted from the HIV Management Plan for Health Services in North Queensland (Apunipima Cape York Health Council 1998).

Contact tracing and partner notification are an essential part of controlling HIV and STI's. Doing this will inform the person who passed on the infection, as well as those who may have acquired it. New infections can be minimised and people at risk or with the infection can be tested and treated.

### Principles

The World Health Organisation Principles of Partner Notification states that notification is acceptable only if the following principles are adhered to.

- The human rights and dignity of each individual are respected.
- Notification forms part of a comprehensive HIV prevention program.
- Notification is voluntary and confidential.
- Adequate support services are available to individuals, including:
  - information about risk;
  - voluntary confidential HIV testing;
  - pre-test information and post-test counselling; and
  - adequate health services.

### Contact tracing issues

#### Who is a contact?

A contact is a person who has had sex with a HIV infected or potentially infected person (someone who has been exposed to HIV and has tested negative to HIV but who, because of the window period, may have HIV and be infectious).

#### How far back should contact tracing go?

1. A person living with HIV should try and recall sexual partners from when they were last known to be HIV negative, or
2. As far back as the client's history indicates is reasonable.

#### Who does the tracing of contacts in the community?

Arrange this in consultation with the client with HIV. Clients should always have the option of notifying contacts themselves or of asking their health worker to do it for them.



If the client wants their health worker to do the contact tracing, how does the worker go about it?

The worker should follow these guidelines.

- Prepare well before approaching anyone. Know every possible detail about the person you are seeking.
- Never tell the name of the index case.
- Respect the confidentiality, privacy and dignity of the person you are seeking.
- Inform contacts that they may have been in contact with someone who has a STI and that they need a check up.
- If someone has left the community, find out where they have gone.

### Who to contact for someone named outside the community

The regional sexual health service can assist with this. Their sexual health workers can do the notifying if the contact is within their area. Get the service to report back with the outcome when they have contacted the person.

### What should contacts be offered?

Contacts should be offered:

- risk assessment;
- safe sex and/or injecting information;
- condoms and/or clean injecting equipment;
- a full STI consultation; and
- a HIV test with pre-test information and post-test counselling.

### What if a person will not name their contacts?

If the person living with HIV refuses to tell contacts, or refuses to give permission to tell contacts (eg "I don't want my wife to know"), the following procedures should be followed.

- Discuss it thoroughly with the person living with HIV, spend time and use every strategy to persuade them to give their permission voluntarily.
- Give them time to think.
- Tell them of the relevant State/Territory legislation that applies in these cases.
- Get advice, talk with local or regional sexual health staff.
- Document in careful detail all your efforts. This should be comprehensive and specific and cover all conversations and actions with the client. This recording may be needed for further action and legal coverage.

Further action regarding this person and their contacts should occur only once the specialist sexual health and relevant health authorities have become involved and provide advice about what to do.

## Further information

Apunipima Cape York Health Council 1998, HIV Management Plan for Health Services in North Queensland, Apunipima Cape York Health Council, Cairns, Qld.

Contact Tracing Manual: A Practical Handbook for Health Care Providers Managing People with HIV, Viral Hepatitis, Other STD's and HIV-related Tuberculosis 1997, DHFS, Canberra.



## Chapter 6

### A multidisciplinary approach to care

#### The care and support needs of people affected by HIV/AIDS

Sometimes the needs of people supporting a person living with HIV can be overlooked because that person's needs seem more critical. However, if carers are well supported and their needs are attended to the support that the person living with HIV receives can be enhanced. People living with HIV/AIDS and affected people such as their partners, family and friends may need access to information and services that include:

- safer sex information;
- everyday living skills;
- treatments information and options;
- information on HIV/AIDS related illnesses;
- community and other supports;
- specific counselling and/or psychiatric interventions;
- drug and alcohol counselling;
- peer support;
- information on statutory rights and obligations;
- specialist medical attention;
- information on social security and benefits; and
- assistance with housing.

Assistance with these matters gives clients more control over their health and lives. Empowerment is an important part of assisting people to feel that they can manage to live and cope with HIV.

Achieving the care and support needs of people affected by HIV/AIDS requires good case management by the health worker and agency. Because it may be difficult for one health worker or agency to meet all of the needs that arise it will be important for the health worker or the agency to build support networks by linking with other specialist services.

#### Stages of support

The types of agencies a health worker might link with are determined by a number of factors, the main factor being the stage that the person has reached with their HIV infection. Early on in HIV infection the person's needs might be mainly for health information and psychological and social support. Therefore, the health worker would concentrate on connecting with agencies that can provide those services and information. Then, when a person is becoming ill and the HIV infection has progressed, the health worker would work with specialist medical, hospital and home care services. A person living with HIV will have many changing needs, and close follow up is required to ensure these needs are met. The needs of those with HIV should be met at all stages of their infection. In order to optimise outcomes, partnerships with other health care agencies are essential.

#### Indigenous health organisations and partnerships

The National Indigenous Australian's Sexual Health Strategy 1996-97 to 1998-99 (NIASHS) recognises that an important part of maintaining high-quality treatment and care for HIV and

other STI's is by strengthening partnerships. This can include the development of formal and informal agreements between Indigenous and mainstream agencies.

The NIASHS stresses that existing support services for Indigenous Australians living with HIV/AIDS are not sufficiently coordinated, are generally under-resourced, and are often not tailored to the needs of Indigenous people. There is a strong belief that, if support service initiatives are to be effective, they must respond to the diversity in Indigenous communities. They need also to ensure the development of support and training mechanisms that are relevant to the needs of the local community.

For many Indigenous community controlled primary health care organisations and Indigenous communities this means that they will be pioneering connections between Indigenous sexual health organisations and mainstream HIV service providers. In some places links and working relationships already exist. At the national level NACCHO and AFAO have signed a Memorandum of Understanding. At State and Territory levels the AIDS Councils have established relationships with Indigenous primary health care organisations to provide them with key contacts for information and referrals.

Specialist HIV treatment units can be found in the capital cities of each State and Territory, and in some regional cities. These units are often located in hospitals or sexual health clinics and employ doctors, nurses, social workers and counsellors who are highly experienced in all aspects of HIV case management. They are also experienced at coordinating with community and home based care services. They could provide a major source of support and advice for Indigenous health workers. The care and support workers at the local AIDS council can provide contact details for these HIV units.

## Networks

Links between Indigenous community controlled primary health care organisations and other health care providers can be created and strengthened to build networks. Such networks can be especially valuable if an agency is working with HIV for the first time, or is a small or remote service.

Some examples of the ways to build networks are shown in the following examples.

To find out about information and services on HIV treatment, care and support, contact:

- the local AIDS Council;
- the local people living With HIV/AIDS group;
- specialist sexual health services; and
- doctors and social workers in the HIV unit at the specialist hospital or clinic.

To build a working relationship with these services:

- ask to be kept updated with all current information;
- offer to be part of consultations in the area;
- ask to participate in relevant staff in-service training;
- ask for resources, publications or conference materials;
- give relevant information regarding Indigenous people living with HIV and AIDS;
- get to know a particular staff member and build a relationship with them to ensure access to information or services as required; and
- ask them to conduct workshops for the organisation.

## Building supportive networks checklist

Consider the following checklist of your support service profile or use it as a guide to make your own checklist.

Have You	Yes	No
Developed partnerships with other organisations that will help care for and support an individual living with HIV/AIDS, dentists, counselling services, health promotion agencies, home care, sexual health specialists, social security?		
Formed relationships with local AIDS Councils, people living with HIV/AIDS organisations, sexual health specialist organisations or with similar types of organisation?		
Collected the names of doctors and health related practitioners in the area with experience in the field of HIV/AIDS treatment, care and support?		
Thought of organisations and people who could help your clients deal with cultural issues and social issues surrounding Indigenous people and HIV/AIDS?		
Identified health workers in your own and other local community organisations that can assist as volunteer carers, peer educators or counsellors?		
Considered asking the client if they want elders or community representatives involved and have listed the names of sympathetic elders who are prepared to assist?		
Considered how to ensure confidentiality regarding the patients status once other people and organisations become involved (might need to establish an agreed partnership code of ethics and protocols)?		
Considered the importance of a plan to ensure that Indigenous people have up to date information on treatments and health monitoring, including printed material and the opportunity to talk to peers and professionals about treatments and health monitoring?		
Developed a list of local care and support services which can be used for clients, such as medical and nursing services, carers, respite care, home help, social security, counselling, community education, spiritual care?		

## Socio-cultural factors

Indigenous community controlled primary health care organisations may need to help educate mainstream agencies about the unique issues that affect the lives of Indigenous Australians and their communities. Doing this will hopefully strengthen the supportive networks and make the casework more effective.

Some of these factors are listed below. They will need to be taken into account by whatever workers or agencies are working with Indigenous people affected by HIV/AIDS.

- Close family ties and the strength of social organisation within Indigenous communities mean that families and communities take a high level of responsibility caring for their own.
- Community caring often takes place in an environment in which there are significant social and economic burdens, such as racism, poverty, unemployment and poor living conditions.
- Caring for people with HIV/AIDS in such an environment often places additional stress on people already dealing with substantial pressures.
- Indigenous people living with HIV/AIDS may choose to move from one community to another, from the city back to a rural community to be with family, or from a remote area to the city to seek better care.
- Discrimination against Indigenous people with HIV/AIDS affects the provision of treatment and care, both within Indigenous communities and in the mainstream.
- Flexible treatment and holistic care approaches are needed to take account of the considerable diversity of circumstances of those infected, including their wide geographic spread.
- Individual, partnership, family and community needs must be approached within a framework that recognises the significance of men's and women's business.
- The treatment choices of people with HIV/AIDS need to be respected and supported.
- Indigenous people may experience difficulty and feel uncomfortable when using mainstream services. This can include visits to hospitals and periods of hospitalisation.
- Culturally sensitive and sound privacy and confidentiality protocols for routine collection of standardised data on Indigenous people should be developed and followed.

## A multidisciplinary approach to care

A diverse range of services is likely to be involved in providing care and support. The health service responsible for providing primary care needs to establish clear systems for coordinating other services. The focus should be on strengthening the capacity of the health service to provide for the needs of Indigenous people living with HIV/AIDS and their carers. The following section describes a typical way in which this is organised. It also has an overview of the common forms of support systems that are used.

## Case management

Case management is where one person (a case manager), takes responsibility for ensuring that the support needs of the client are met. This is done, of course, in consultation with the HIV positive person.

The case manager's role is to limit the need for HIV infected and affected people to deal with many different health service providers. The case worker provides information and arranges services for their client rather than have the client trying to gather information and negotiate care and support services with each of the health service providers involved. Thus the case manager will need to be aware of the full range of services that exist and have connections with them.

An important aim of a case manager is to ensure continuity of services for the person living with HIV or AIDS. This means that the case manager will need to do some forward planning, anticipating the types of services the client may need in the future, and establishing connections with these services in anticipation of their client's need.

The case manager should be easy for the client to access. At all times the client should be informed of options and in control of decision making.

The HIV/AIDS case manager could be someone working in Indigenous primary health care organisation, someone with specific responsibility for HIV care, or someone working in another health care setting.

### A multidisciplinary health care team

A shared-care partnership is the preferred system for coordinating services. In the shared-care partnership, the caseworker draws upon and involves other expertise and services. Some examples of how this can function are listed below.

- If the primary health care giver is inexperienced with HIV clinical management, most decisions will involve consultations with a HIV specialist, who also would inform the primary care giver and infected person about treatment advances.
- Many people with HIV will require admission to hospital at some stage, preferably under the care of a physician with HIV experience. In preparation for this, the infected person should get to know the doctors involved in their treatment as early as possible.
- Communication between all people involved in case management should be worked out, with an emphasis on learning from the knowledge and experience of others, in order to build up the expertise and confidence of all those involved.

### Be quick to enlist other professional support

There are many ways in which other expertise and services can become part of the multidisciplinary team. These can include:

- Issues such as detection of HIV infection, first AIDS defining illness, various psychological and physical crises, and loss of employment could all require the services of a counsellor.
- Housing and accommodation can be problematic, requiring housing services to be involved.
- Regular dental care is important, as mouth problems are common. Finding a dentist who is comfortable working with HIV is the case manager's responsibility.
- In the later stages of illness, the assistance of community support workers is vital to work through the care and support needs of individuals and their families.
- Home-based care is an important aspect of advanced disease. This requires close liaison between different care and support services.

## Issues for isolated and remote area health services

Health services in isolated and remote areas may experience problems which are amplified due to their geographical location. They issues can include providing services to cover a large region, under-resourcing, and high staff turnover. The Indigenous people in the region may be quite mobile and travel from community to community and use different health services. In these situations it is worth considering using regional resources to coordinate care and support activities.



## Different types of support

During the course of HIV infection people can need, or benefit from, different forms of support. This can apply both for the person living with HIV and family or friends providing the main support. The following section describes some different types of support services.

### Buddy systems

'Buddies' or friendly visitors can provide an extra form of support. In most major cities there are programs that coordinate trained volunteers. These volunteers provide social and emotional support, often committing to spend regular time with the client. These groups can be contacted through the AIDS Councils.

### Carers

A carer is someone who provides assistance to people with acute HIV infection or someone who is in the later stages of disease. Carers might help people with HIV/AIDS with, for example, personal hygiene, eating, bathing, mobility, and domestic chores. These carers are usually coordinated through the AIDS Council in that State or Territory. They are volunteers who have been trained in providing care as well as in matters such as confidentiality and how to be involved in other people's homes and lives.

Some forms of home care are available through local councils or through agencies that specialise in medical care in the home. These vary from region to region. Details should be available from hospital social workers, community health centres or AIDS Councils.

### Home care

Home care programs aim to strengthen and support the patient and the family and to facilitate the family's caring role. When planning for home care strategies, consider the following:

- Check that families and communities are willing to provide care, and that the person requiring care wants it to happen that way.
- Community education aimed at decreasing the stigma associated with HIV/AIDS diseases is a prerequisite for setting up a home care program.
- Providing training which enables people to be cared for at home is an essential component of program planning. Most AIDS Councils have training programs for home care.

The kind of care provided at home may include the following.

**Medical and nursing care** Usually involves a team of clinical practitioners who diagnose clinical problems and prescribe medication in the home.

**Counselling** Individual, family and community counselling is an integral part of home care services. Counselling could include providing basic information and advice to partners and family members who may be worried about aspects of HIV; informing the person living with HIV/AIDS about positive living and self-care; and assisting families to provide effective care and support.

### Material Support

Providing assistance with food, clothing, bedding, medicines, electricity and telephone bill and other such costs. Many people with HIV infection are reliant upon family members and community members for material support. Provision of the 'home basics' is an essential part of a home care program. Many AIDS Councils can provide some financial and material assistance.

### Spiritual care

Aimed at meeting the spiritual needs of infected and affected people. This can be offered through the churches in the area or through traditional and cultural practice, as defined by the person receiving care. Some major HIV treating hospitals have chaplains on their HIV team.

### Palliative care

The best palliative care will usually involve a balance between pain relief, maximum comfort, and maintaining the best available treatment. This can be provided in the home or in special palliative care units. Associations in each State and Territory coordinate palliative care and offer information and resources about what is available. Contact for palliative care organisations can be made through local hospitals, community health care centres or the AIDS Council.

### Respite care

When friends and relatives are involved in providing home care and support to a person living with HIV or AIDS, a rest, or respite, from caring will often be necessary from time to time.

Carers and those being cared for, may need help or a reminder to understand this, so that a rest from caring can be taken without too much guilt, blame or distress, and so that appropriate respite care is available when needed.

Respite care can take different forms. Other people can take over responsibility for home care for a period, allowing the primary carers to have a break. The person with AIDS can be admitted to hospital to give those at home a rest. In some places it is possible for people with AIDS to be admitted to special respite care centres or hospices. Further information can be provided by the doctors or hospitals providing the care or from AIDS Councils.

### Peer support

Many people with HIV/AIDS want to talk with someone in the same position. Peer support gives HIV positive people a safe, non-judgmental environment where they can talk about and share their experiences with other HIV positive people. This can increase their knowledge about HIV and help to reduce the frustration, stigma and shame that can be associated HIV/AIDS. Above all, it helps people to feel less alone and isolated.

Over recent years more and more Indigenous people with HIV/AIDS have become public about their HIV status. They have spoken at Indigenous and mainstream conferences and forums and in the media. They also participate in some People Living With HIV and AIDS organisations such as People Living with HIV and AIDS (PLWHA) or NAPWA (National Association of People Living With HIV/AIDS) (NAPWA). NAPWA has a specific place on its Executive for an Indigenous representative. These contact details can be found in appendix 4.

An Indigenous person living with HIV/AIDS may find it uncomfortable to just turn up to some of the peer support groups. It may be easier to begin contact through the staff that provides the back up for these groups. Often these staff are also responsible for providing one on one contact for people with HIV/AIDS. They may be able to develop strategies that might be more appropriate for Indigenous people and arrange contact with other Indigenous people with HIV.

Many PLWHA organisations conduct groups and workshops on issues that affect the lives of people with HIV/AIDS. These workshops vary but can include updates on treatments and information on nutrition, handling relationships, referral to services, and access to social security.

So far in Australia there is not an established peer support group for Indigenous people with HIV/AIDS. Should some individuals or organisations want to create a peer support group NAPWA has kits that can assist in establishing and running such a group.

The other thing about peer support groups is that, over time, they often give people the confidence to take a more active role in the overall response to the HIV epidemic. This has been an important component of what has occurred so far in Australia. Much that has been learnt about the epidemic and the best ways to respond to it have come from those people with HIV/AIDS. It has been very valuable to have them on all committees and planning groups. They have a unique ability to express what needs to happen and why. This is one outcome of encouraging people's involvement in peer support. A similar thing is happening as more Indigenous people get involved in peer support. This will help develop better understandings of what is required for an Indigenous community based response to the HIV epidemic.

The following box contains examples of the types of services and people that could become involved in providing care and support. It can be a useful checklist.

- HIV Testing and Counselling Services
- Primary Care Doctor
- Hospital-based Specialist
- Outpatient and Ambulatory Services
- Dental Health Services
- Mental Health Services
- Counselling and Peer Support Services
- Community and Home Care Services
- Carer Support Services
- Elders or Community Representatives (if involved)
- Traditional Healer
- Social Security
- Nutritionist
- Palliative and Respite Care Services
- Contact Tracing
- AIDS Councils
- People Living With HIV and AIDS Organisations

## Further information

### Information on HIV and all aspects of medical management

Stewart, G. (ed) 1997, *Managing HIV*, Australasian Medical Publishing, North Sydney, NSW.

Comprehensive coverage of HIV disease, essential reference and resource material for every health service.

Available from: Australasian Society for HIV Medicine (ASHM),  
PO Box 166 Randwick, NSW 2031.  
Tel: (02) 9382 1656 Fax: (02) 9382 3699.

Positive information for patients, n.d., CD ROM.

Information for doctors on all information required by a person living with HIV/AIDS.

Available from: Australasian Society for HIV Medicine [ASHM],  
PO Box 166, Randwick, NSW 2031.  
Tel: (02) 9382 1656 Fax: (02) 9382 3699.

### References/resources for counselling in Indigenous communities

Augustsson, Cheryl (comp) 1996, *AIDS Sickness: Information for Yamatjis*, Gascoyne Public Health Unit, Carnarvon, WA.

Available from: Gascoyne Public Health Unit,  
Cnr. Cleaver & Johnston Streets, Carnarvon, WA.  
Tel: (08) 9941 0560 Fax: (08) 9941 0563

Department of Health and Aged Care (DHAC), Office of Aboriginal and Torres Strait Islander Health 1999, *STD Control in Remote Aboriginal Communities: A Manual for Clinic Workers*, DHAC, Canberra.

Available from: Department of Health and Aged Care,  
PO Box 9848, Canberra, ACT 2601.  
Tel: (02) 6289 8101 Fax: (02) 6289 6838.

Department of Health, Housing and Community Services (DHHCS) 1992, *HIV/AIDS: National Counselling Guidelines*, AGPS, Canberra.

Chapters include pre-test counselling, giving results, needs of people affected by HIV, and long-term counselling.

Available from: Publications Officer, Public Health Education Unit,  
National Centre for Diseases Control,  
GPO Box 9848 (MDP 15), Canberra, ACT 2601.  
Tel: (02) 6289 8101 Fax: (02) 6289 6838.

Miller, Riva, & Bor, Robert 1995, *AIDS: A Guide to Clinical Counselling*, Current Science Press, Philadelphia, PA.

Available from: The University Cooperative Bookshop,  
80 Bay Street, Broadway, NSW 2007.  
Tel: (02) 9325 9660 Fax: (02) 9325 9667.

This may also be available through medical book suppliers.

## Regional HIV testing, policy procedures, protocol manuals

Alice Springs Remote Health Services 1997, HIV Testing Manual, Alice Springs Remote Health Services, Alice Springs, NT.

Available from: The Sexual Health Unit,  
PO Box 721, Alice Springs, NT 0870.  
Tel: (08) 8951 7550 Fax: (08) 8951 7555.

Apunipima Cape York Health Council 1998, HIV Management Plan for Health Services in North Queensland, Apunipima Cape York Health Council, Cairns, Qld.

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PO Box 2797, Cairns, Qld 4870.  
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PO Box 902, Cairns, Qld.  
Tel: (07) 4050 6205 Fax: (07) 4050 6359.  
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Tel: (07) 4050 3600.

## Chapter 7

### Developing HIV/AIDS policy and procedures

This chapter is about how to develop policy and procedures within a health service. Having HIV/AIDS policy and procedures in a health service ensures an established model of service delivery. Having agreed protocols and strategies in place for all health care workers ensures that they have the capacity to manage the needs of people living with HIV/AIDS and their families and communities.

There are a number of reasons why it is important to develop clearly understood procedures. Evidence shows that the needs of Indigenous people with HIV/AIDS and their families, partners and carers are not being satisfactorily met.

This is probably due to poor access to the latest treatments and not having their health monitored properly by HIV specialists. It could also be due to a reluctance to be tested for HIV for fear of the shame associated with it. It can also be affected by other health problems, such as diabetes and renal disease, which also compromise immune function, and the high burden of infectious disease, especially in remote communities.

For these reasons it is important that Indigenous community controlled primary health care organisations develop procedures and protocols. They can have a direct effect on the well being and life span of their clients. Good procedures will mean clients get the best service and attention available, and so have a better quality life. Also, if a service has good procedures people will feel confident in accessing that service.

Some services will have specific difficulties. In some places geography and isolation will present challenges, in others it may be difficult to devote the staff, resources and time needed to develop policies and procedures. The value of developing ways of overcoming these difficulties, to provide the procedures and protocols which will underpin the best possible care for those people with HIV or AIDS, cannot be underestimated.

### Benefits

Good HIV policies and procedures will not only assist health workers to handle HIV work well but also will have spin-offs in many other areas. For example, policies and procedures can be a part of overall STI strategies; they will assist in addressing sexual health issues in the community; attention to confidentiality will improve people's confidence in the whole service; and interaction with the community in developing the policies will provide vital education and awareness about HIV and STI's.

The detail and steps in the following section may appear overwhelming and too difficult to achieve. A lot of detail is included because HIV is a complex matter. Each agency needs to take the time to understand why these policies are important and to ensure that staff understand and implement them.

## Why are policies and procedures necessary?

The following reasons have been given to explain why Indigenous people do not go for HIV testing.

- Evidence exists that Indigenous people are unlikely to present to health services if there are no appropriate mechanisms in place, such as confidentiality, counselling and an organised referral network, to respond to positive HIV test results.
- Some services can lack an understanding of the support needs of Indigenous people who are HIV positive.
- Advice and education resources about treatment options are minimal.

This means that Indigenous people do not get diagnosed early in their HIV infection and so may not benefit from the latest treatments. This could mean that they become sick faster and die earlier than other Australians with HIV.

This information shows why it is necessary for organisations to develop policies and procedures for managing HIV. It also shows where policy should begin. Going to the people, the community, is the starting point for developing appropriate policies and procedures.

## Developing HIV/AIDS policy and procedures

### Step 1: map the process

To begin, the organisation should take a long-term view of what will be involved in developing HIV policies and procedures. This will require attention to the following topics:

- Deciding why the organisation needs HIV/AIDS policies.
- Deciding who will be responsible for the process.
- Establishing timelines for the work involved.
- Planning how to involve the community.
- Setting up working groups.
- Determining if it is possible to involve those with and affected by HIV (allowing for confidentiality, or possibly having an Indigenous person living with HIV visit from elsewhere for some awareness raising and education sessions).
- Identifying what resources, advisors or examples of policies from other organisations might be required.

### Step 2: educate

Educate the staff and community about HIV/AIDS. Many people are still confused about the basic facts of HIV. They can still be affected by many of the myths about HIV, and may have beliefs and attitudes that hinder productive work developing. Establishing basic education programmes on HIV for staff and the community will:

- ensure that everyone has a common understanding about HIV and the need to develop policies and services;
- identify the key areas of concern for the community and strategies for action;
- establish community support for the work the health service or organisation does; and
- enhance the level of community support for those affected by HIV/AIDS.

### Step 3: identify the role of the organisation

At this stage the organisation needs to decide what HIV/AIDS service it can realistically provide.

This decision should be taken with care and thought and should be based on an appreciation of what resources the organisation has, and what resources are already available in the region.

At this point the organisation should consider the following:

- What are realistic roles and responsibilities for this organisation in providing care and support for those affected by HIV? Some organisations may decide that they would be better off by getting regional services to coordinate care and support.
- Develop a Statement of principles for the health service. This will be the guide for the details of the policies and procedures that are developed next. It is the message that is given to the staff and community about what the organisation sees as its role (appendix 2 contains some examples of Statements of principles).

#### Step 4: identify what policies are needed

At this stage the organisation can identify the policies it will need to do its work properly. It should also identify what process is needed to get these policies to match their requirements. It also helps to establish some timelines for this so that progress can be monitored. Some typical areas needing policy are:

- confidentiality;
- community law;
- shame;
- judicial law;
- Occupational, Health and Safety (OH&S) for health centre staff and clients;
- pre- and post-HIV antibody test counselling;
- professional training;
- HIV antibody testing procedures (OH&S and confidentiality);
- discrimination;
- social issues;
- employment and housing provision; and
- community issues.

There should also be policies specifically for clinical practice, including:

- universal precautions(to avoid infection);
- needlestick and blood accidents protocol;
- ethics process for research proposals;
- release of medical information; and
- sharps disposal.

The procedures for providing HIV test counselling in Chapter 3 are examples of the details to include in creating policy for providing testing and counselling. Appendix 2 contains a checklist that can assist in deciding what policies an organisation may wish to develop.

Some examples of typical HIV policies include:

#### Harm reduction

This approach is based on the belief that if people are doing things that put themselves at risk and do not wish to change their behaviour, then the best approach is to try to reduce the risk associated with that behaviour. For example, it may not be possible to persuade people to have fewer sexual partners; however, it may be possible to persuade them to use condoms. In this way you are reducing their risk of contracting STI's and HIV. Similarly, you may not be able to stop people from injecting drugs, but you can try to ensure they know about, and can get, new injecting equipment, so they are not at risk of sharing equipment and contracting HIV and/or hepatitis C. This minimises the harm they are exposed

For a primary health care organisation, the harm reduction approach might mean that they think about how people are educated about, and have access to, condoms and clean injecting



equipment. Some organisations might then decide to run education campaigns about this; some may decide to distribute condoms and new injecting equipment.

### Clinical care

Some organisations may decide to adapt a policy on clinical care for those with HIV along the following lines:

- Ensure that treatment is based on the best, evidence based practice, including the development and use of appropriate clinical care guidelines for diagnosis and management of STI's.
- Use new, less invasive diagnostic technology to simplify STI testing processes.
- Remove the barriers that prevent the screening of non-symptomatic clients.
- Prescribe HIV treatments that suit adherence (taking HIV medication at the recommended times).
- Adopt an understanding of, and commitment to, appropriate confidentiality processes within services; for example, adopting a coding system for managing HIV.
- Institute pre- and post-HIV test counselling guidelines to ensure that people tested for HIV give informed consent.
- Reduce the risk of disease transmission in the primary health care setting (universal precautions).

### Step 5: putting policies into practice - establishing procedures

Once policies have been created, an organisation will need to look at how they can be put into practice. This means looking at the steps required for an organisation to conduct work in a particular area. For example, if an organisation has a confidentiality policy, then a step is required to identify the procedures and practices that need to be put in place and followed to ensure that confidentiality is maintained.

The organisation should look at its list of policies and then work through and develop the necessary procedures to ensure that policies are incorporated into practice

Some examples of procedures are listed below.

### Case management

An organisation might decide that clients will be handled by a case management system. Case management might include the following:

- One person, the case manager, will take overall responsibility for a client.
- The case manager's role is to reduce the need for clients to have to deal with a range of service providers.
- The case manager will develop a plan with the client that identifies their range of needs.
- The case manager will be responsible for coordinating liaison with all the services the client needs.

## Step 6: communicating policies and procedures

When the policies and procedures have been developed an organisation should establish strategies to ensure they are acted on and that the relevant people are informed about them. The processes might involve:

- creating a policies and procedures manual, and distributing to all staff;
- training staff to follow policies and procedures;
- establishing an induction system for all new staff to be informed of the policies and procedures;
- informing the community of the policies and procedures; and
- inform other relevant organisations.



## Chapter 8

### Training and development

Appropriate and continued education and training for all workers, both paid and unpaid, is needed in order to provide quality care and support to Indigenous people with HIV/AIDS. Since diverse knowledge is required to provide a complete service for people with HIV/AIDS, health centre management must establish systems for training and development.

These systems should ensure appropriate training is provided to allow people to fulfil their roles. This needs to cover both staff and those in the community involved in HIV work. These community people can be volunteers, as well as those close to and caring for those with HIV/AIDS.

Issues to consider concerning training and development should include the following.

- The recruitment of HIV/AIDS support workers should include efforts to encourage older members of communities to take on such positions.
- In recruiting workers, every effort should be made to establish a gender balance.
- Specific strategies can help staff avoid burnout, including job sharing, extended leave, part-time work, proper debriefing, extended networking and supports, training workshops and access to appropriate educational resources.
- The use of mainstream services to provide support to staff and volunteers until the time when more culturally appropriate support and de-briefing services can be developed.

### Organisational systems for training and development

Each organisation needs to establish policies about the type and level of training needed to fulfil the various services that the organisation provides.

These policies will range across a number of areas, including:

- clinical care and management;
- HIV testing and counselling;
- education skills;
- training for carers;
- Occupational Health and Safety.

Some examples of training standards from HIV Management Plan for Health Services in North Queensland (Apunipima Cape York Health Council 1998) are:

#### Staff training in the area of HIV: minimum standards

- At least one of the visiting (or health centre based) medical officers (eg RFDS) has attended a HIV prescribers course.
- At least two members of the nursing staff and of the health worker staff attend an in-service on HIV/AIDS each year.
- All health service staff doing HIV antibody testing have received training in pre- and post-test counselling and post-test information.

## Guidelines for Occupational Health and Safety

- The district OH&S officer (or equivalent) provides regular in-services at each health centre (annually).
- The manager provides each new staff member with the OH&S protocols for the health centre and ensures that she/he attends the next possible OH&S in-service.
- The manager provides the information, equipment and training for staff to ensure the implementation of all the recommended occupational health and safety guidelines.

## Maintenance of resource materials

Having access to a range of resources can be essential for both workers and clients. For workers this can involve access to technical information that can assist them to conduct their work. Examples of this would be manuals and reference materials. Also, having access to a range of educational material can assist them in education and other work with their clients.

Resources for assisting with HIV/AIDS issues should include more than just books and written material. Because of varying literacy levels in many Indigenous communities it can be useful to have copies of the videos, comics and posters that have been made around Australia. This can also assist in the development of appropriate local level information.

Some ways in which resource collections can be built up include:

- keeping an up-to-date register of resource people willing to assist the health service and the HIV/AIDS programs.
- maintaining a register of resource materials with information on HIV/AIDS, including technical and counselling manuals, and training information for health workers, carers and volunteers.
- establishing a HIV library that contains a range of HIV educational material.

Indigenous primary health organisations have produced a range of resources to provide education about HIV/AIDS. While some of these resources have been made especially for certain communities and so use specific culture and language, there are others that can be used across different communities. They can be accessed through local Indigenous sexual health workers and local Indigenous community controlled primary health care organisations.

Appendix 3 on Training and Staff Development has contact details for further training.

## Reference

Apunipima Cape York Health Council 1998, HIV Management Plan for Health Services in North Queensland, Apunipima Cape York Health Council, Cairns, Qld.

## Chapter 9

### Community education

#### Importance of on-going community education and consultation

One of the main lessons health workers have learnt about responding to HIV/AIDS is the key elements of this disease, education, care and stigma are intricately connected. If people are uncertain about HIV, and about how it is transmitted, often they will fear it. Usually this fear means that they are frightened of those who are infected. This can lead to discrimination and rejection. People who are ignorant or uncertain do not realise how they, or their families, might be at risk of infection, and don't change to safe behaviours. So the virus continues to spread.

Thus the basis of any community program on HIV has to be a strategy that assists everyone's understanding of HIV/AIDS and how it can affect them and their community. This means that people need information and knowledge to talk about a whole range of different issues. There are often taboos about the very subjects that need to be addressed in HIV education: sex, sexuality, faithfulness in relationships, and injecting drug use.

Attitudes are often the same the world over when it comes to HIV and AIDS. There can be a lot of fear and uncertainty, and people can react negatively to those with HIV/AIDS. Consequently, many Indigenous people may be frightened of what might happen to them should they become HIV infected, or known to be infected, and so may be reluctant to seek help or testing. This can compromise the management of a person living with HIV/AIDS.

There are however examples of Indigenous community controlled health organisations which have carried out extensive consultation, education, and policy development with their communities. Through these processes, these services now have developed community policies to protect confidentiality and care for people living with and affected by HIV/AIDS.

Consultations with communities about HIV can be difficult. HIV is something that affects people's attitudes and beliefs. People often need time to understand all the issues around HIV/AIDS. One of the things that has the biggest effect on people is when they know someone who is living with HIV or AIDS. There is an understanding that HIV is real and that it could affect them or someone in their family or community. For these reasons many education programs try to include someone who can tell their story, whether that be a person living with HIV or a family member, loved one or carer. Confidentiality is very important when someone has the courage to do this, and the health worker has the responsibility of ensuring that the person is protected and appreciated.

### Community education

The following processes and issues should be taken into account when developing community education strategies (adapted from Risky business workshop (Arabena 1996), TriState Project, Alice Springs):

- discussions about what puts people at risk;
- traditional concepts of health and confidentiality;
- how to develop personal and collective risk reducing strategies;
- individual and community problem solving in the areas of STI and HIV transmission;
- discussion on HIV/AIDS being an important health issue for Indigenous people and not only a non-Indigenous community problem;
- resourcing for communities with specific education materials;
- information which supports a positive endorsement of safer sex messages in the community;

- ways of making condoms more accessible, cheaper, and more acceptable for use in the local community and at a regional level;
- reinforcement of the caring and just values of the community by working across generations; and
- ways to create an environment of tolerance and acceptance towards people with HIV/AIDS.

## Ongoing community participation

Education and consultation sessions with the community are just one part of having a good interaction between a health service and the community. Initiating a number of other strategies that are designed to facilitate ongoing participation can strengthen this relationship. Doing this ensures that the community continues to have its needs expressed at the health service level. It also builds community support confidence in their health centre.

Examples of such strategies include:

- community representation on management and steering committees, and working groups;
- volunteer participation in special events; and
- elder and community leader involvement to facilitate understanding and support.

## Reference

Arabena, K. 1996, Risky business: Workshop participants book, Tri-State Project, Alice Springs, NT, unpublished.

## Chapter 10

### The needs of children

In many Indigenous cultures, it is common for children to be cared for by their traditional auntie's, uncles and grandparents. The extended family network has to a large degree made caring for children who have lost parents relatively easy.

In other countries where HIV is having long-term effects some 'unfamiliar' types of families are being created. Because the parent generation has died, some households are made up only of the very young and the very old or are headed by adolescents.

### Children living with HIV/AIDS

There are particular and special issues associated with children living with HIV or AIDS.

For children born of a mother living with HIV, it can take up to eighteen months to confirm if the child is infected or not. This is because the child will be born with their mother's antibodies, and this will show as positive in the child's HIV tests. By the age of eighteen months a child's own antibodies can be tested. This period of waiting causes much anxiety for parents and family.

For 20 per cent of HIV infected babies there is a risk they will develop AIDS in the first year of their life. After that, for the other 80 per cent, it appears that their course with HIV infection is similar to that of adults. It is likely that many of them will reach adolescence and some will reach adulthood (Stewart 1997).

Children with HIV are also treated with combination antiretroviral therapies and have similar responses to those of adults.

Sometimes a child is diagnosed with HIV because it is not healthy and so is tested and found to have HIV infection. This can be the first time that the family learns that HIV is present in the family. Subsequent tests usually show that the mother, and possibly the father is living with HIV. This causes enormous stress within the family as these diagnoses can all occur within a short period.

### Issues for consideration

In addition to the issues faced by any adult with HIV, the diagnosis of a child living with HIV is highly stressful for the whole family. Health workers involved in supporting a child living with HIV could consider the following issues:

- Parents and other family members can become preoccupied with blame, guilt and denial, which add to the already high demands for care.
- It is important to assess family members understanding of HIV and to combine this knowledge with the medical demands of treatment.
- Parents should be encouraged to be active participants in planning and conducting the care of the child, and the need to access support and counselling to provide sustained emotional and physical load of caring for a child living with HIV.
- Arrangements for adequate child care for other children when conducting consultations with parents of a child living with HIV.



- Parents living with HIV/AIDS may die or become severely ill before their child living with HIV, and adequate care from extended family or foster care needs to be arranged in time.
- Disclosure of a child's HIV status needs to be controlled and coordinated between family and service providers, including providers of education or mainstream childcare. The providers may require education, support and the opportunity to ask questions around the time of disclosure and through ongoing care.
- The needs of non-infected siblings and other family must not be forgotten, including their need for attention from parents and their needs associated with coping with anxiety and stresses.
- HIV infected children need to understand their own status in a way that makes sense to them at their stage of development. This means providing appropriate opportunities for play, stories, and other means of learning about their own condition and how it affects them (Stewart 1997).

## Parents living with HIV/AIDS

If a parent is living with HIV, or has primary responsibility for a child or children, strategies are needed to help them deal with this particular range of issues.

Families and communities are often the first to respond to the needs of children in families affected by HIV. Programs should aim primarily to support and, where necessary, establish sustainable family and community based support and care responses. Programs should try to meet the full range of children's psychological, social, material, legal and spiritual needs. The forms of strategies can include the following:

- Parents should be encouraged to develop comprehensive plans for their children's future. This may involve talking to relatives, accessing counselling services and allowing parents the time to consider their options.
- Support should be offered to parents to help them secure their children's financial future. Possible strategies include helping them maintain employment for as long as possible and assistance with financial planning.
- Implement processes to protect children's inheritance and legal rights to enhance their security and well being.
- Every effort should be made to prevent the break up of families. Extended families, relatives and community institutions should be given support to help meet the special needs of orphaned, displaced and abandoned children, and extra efforts should be made to ensure that no child is treated as an outcast.
- Emotional and psychological support is essential for children who are feeling abandoned, guilty, or who are suffering depression as a result of their loss.
- Basic material support should be provided within a child's own community, family and familiar settings.
- Long-term care and support services should be instituted for children whose parents have passed away from AIDS.

In some of the major cities there are medical units that specialise in children living with HIV or AIDS. In these settings there are experienced doctors, nurses, social workers and counsellors who specialise in providing care for children living with HIV/AIDS. These units should be contacted when managing cases involving children affected by HIV/AIDS.

## Reference

Stewart, G. (ed) 1997, *Managing HIV*, Australasian Medical Publishing, North Sydney, NSW.

# Appendix 1

## Taking care with language and terms

It is important to use the correct words and language when talking about HIV and AIDS. Many people are confused about HIV and AIDS and the correct use of language can clarify issues for them. Some language can be offensive to those affected by HIV/AIDS. The following list contains some of the main examples of the confusion that can arise with language and terms.

### AIDS (when confused with HIV)

People can use the word 'AIDS' when they are really talking about HIV. It is worth reinforcing the difference between HIV and AIDS. AIDS is a complex set of conditions which occurs when a person's immune system is seriously damaged by HIV infection. Someone who has HIV infection may not have developed the illnesses that constitute AIDS. It may take 10 years or more for someone with HIV infection to develop AIDS.

Alternatives: HIV infection; HIV positive; or HIV/AIDS.

### AIDS carrier

This term is highly stigmatising and therefore may be offensive to many people with HIV and AIDS. It is also incorrect; people 'carry' HIV.

Alternatives: Person living with HIV; or person living with HIV or AIDS (PLWHA).

### AIDS patient

Uses only where appropriate. Use 'AIDS' patients to describe someone who has AIDS and who is in a context where they would be a patient, such as in a medical setting. Most of the time, a person with AIDS is not in the role of patient.

Alternatives: Person living with HIV or AIDS.

### AIDS victim or AIDS sufferer

The term 'victim' implies that people with HIV and AIDS are powerless, and have no control over their lives. For similar reasons, many people dislike being referred to as AIDS sufferers.

Alternatives: Person living with HIV; or person living with HIV or AIDS.

## AIDS virus

It is better to talk about the HIV virus. This reminds people of the difference between HIV and AIDS. However, in some regions Aboriginal people speaking languages specific to their area may use an alternative reference; for example, in the Kimberley the term 'AIDS germ' is used.

Alternatives: HIV; HIV infection; HIV disease; or the germ that causes AIDS.

## Bodily fluids

Always explain which bodily fluids contain HIV in sufficient concentration to be implicated in HIV transmission (blood, semen, vaginal fluids and breast milk). It is generally agreed that HIV cannot be transmitted through other bodily fluids such as saliva, sweat, tears or urine. Providing clear information is the first basic step in helping people understand HIV and AIDS

Alternative: Be specific about which fluids.

## Full-blown AIDS

This term implies that such a thing as 'half-blown' AIDS exists. A person only has AIDS when they present with an AIDS defining illness such as an opportunistic infection.

Alternatives: Person with AIDS; or person living with HIV infection.

## High-risk group

This term implies that membership of a particular group, rather than behaviour, is the significant factor in HIV transmission. This term may lull people who don't identify with a high-risk group into a false sense of security. It is high-risk behaviours such as unsafe sex, or unsafe needle, syringe or other injecting equipment use that can spread HIV ñ not high-risk groups.

Alternatives: Affected communities; high-risk behaviour (unsafe sex, shared needles, syringes or other injecting equipment).

## Innocent victims

This is usually used to describe HIV positive children or people with medically acquired HIV infection. It wrongly implies that people infected in other ways are guilty.

Alternatives: People with medically acquired HIV or AIDS; children with HIV.

## Appendix 2

### Policy checklist

### Developing a Statement of principles

A good first step for any policy writing is to determine the organisation's philosophy about HIV, and then produce a clear and strong Statement that outlines this philosophy. For example (this organisation believes in the philosophy which recognises the rights of people living with HIV/AIDS and this determines the attitude with which the organisation will treat positive people.

Such a Statement acts as an example by showing that there are positive approaches that can reduce the stigma and discrimination faced by people living with HIV/AIDS.

Sometimes it is best to develop a Statement of Principles over time. Begin by outlining the areas and topics the Statement needs to cover. As policies are developed, and people become more informed about HIV, go back to the Statement and put in the words that will reflect what is appropriate.

A sample Statement of Principles is included in this appendix. These 'Guiding Principles for treatment, care and support for people living with HIV/AIDS' comes from the National HIV/AIDS Strategy (DHFS 1996).

An example of another Statement is from HIV Management Plan for Health Services in North Queensland (Apunipima Cape York Health Council 1998). It's Overall Aims and Philosophy Statement is as follows:

- All people in the Northern Health Zone with HIV infection or AIDS will have access to the best possible care and support in a community of their choice whether this be urban, rural or remote.
- All health care centres in the zone will provide the best possible clinical, counselling and supportive care for people infected or affected by HIV.
- All health care centres in the zone will provide services for HIV infected people that are not discriminatory.
- All health care centres will adopt best practice to minimise the spread of HIV in the community.

## Developing policies and procedures

Consider the following checklist to help with an overview of what policies and procedures might be needed in an organisation.

Have You	Yes	No
As an organisation, worked out the likely consequences of a positive diagnosis in your community?		
Put in place appropriate clinical systems to increase confidentiality about HIV testing such as number coded systems, separate HIV folders, who will be responsible for ordering and opening a HIV positive result et cetera?		
An internal HIV policy that has been adopted through appropriate community consultation and follows best practice/national guidelines?		
Put staff confidentiality clauses in employment contracts?		
Helped all staff access appropriate HIV training, orientation programs, and in-services about HIV?		
Made your service easy to access with separate entrances, private consultation rooms, and space enough for carers and families to be present when people access your service?		
Considered the models of HIV management your service will adopt?		
Looked at how you will implement the HIV clinical management strategies outlined in the manual?		

Have You	Yes	No
Entered into partnerships with other organisations/service providers, such as dentists, dieticians, and mainstream health services, who will help with care?		
Consulted with people living with and/or affected by HIV/AIDS in the development of your programs and asked them to participate in education programs, or evaluation of the services?		
Formed relationships with local AIDS Councils, specialist health services or other organisations to find ways of improving your services?		
Access to appropriate debriefing and counselling for staff and carers, as necessary?		
Considered the employment of a case manager for people living with HIV and their families to coordinate between services?		
Developed a case management plan with your organisation and other service providers in the area?		
Developed a multidiscipline approach to treatment, care and support issues for people in your community?		
Thought about ways to help your clients deal with cultural issues that are important, such as relocation, discrimination, social isolation, going home to die, participating in men's and women's business, et cetera.		
Information about accessing and participating in clinical trials in the area?		

Have You	Yes	No
Culturally and language appropriate pre- and post-test counselling tools/resources/protocols that your staff feel comfortable in using?		
Negotiated between staff members about how this test information will be returned to the person who requested it?		
Guaranteed that your health service will provide effective confidentiality and privacy mechanisms and, if so, by what means?		
Ensured that all the counselling needs of the infected and affected people have been addressed and dealt with?		
Provided information in a format that your client can use and understand?		
Completed a staff development and professional development program for all staff in the organisation?		
Worked out the roles and relationships between the health care providers (doctors, health workers, nurses) and established organisational policies to meet these responsibilities?		
Organised respite care for people who need it?		
Identified the need for volunteer carers, buddy systems, peer educators and put some strategies in place?		
An information folder with all the names of people and places you can use or refer clients to on a regular basis?		

## Guiding Principles for Treatment, Care and Support For People Living with HIV/AIDS

1. People living with HIV/AIDS have the same rights to comprehensive and appropriate health care as other members of the community, without fear of discrimination.
2. The needs of groups of HIV positive people who may experience difficulty in gaining appropriate services such as Indigenous people and women need to be met.
3. People living with HIV/AIDS have a right to be involved in the planning and implementation of treatment and care programs. This should include representation on relevant bodies.
4. The balance between general and HIV specific services will change as the health system's capacity to provide high quality treatment and care for people living with HIV/AIDS continues.
5. Early intervention and health maintenance and monitoring should be the basis of best practice guidelines.
6. The training of health care workers, both professional and volunteer, should continue. HIV related conditions and treatments are very specialised and developments proceed rapidly.
7. Community based volunteer services should be encouraged and supported: they are integral to the community care network.
8. The model of HIV treatment and care should be a model for related communicable diseases, sexually transmitted infections and other serious chronic conditions.

Source: DHFS (1996).

### References

Apunipima Cape York Health Council 1998, HIV Management Plan for Health Services in North Queensland, Apunipima Cape York Health Council, Cairns, Qld.

Department of Health and Family Services (DHFS) 1996, Partnerships in Practice: National HIV/AIDS Strategy 1996-97 to 1998-99, DHFS, Canberra



## Service delivery

This exercise might assist to identify what the organisation's roles and responsibilities will be in providing HIV/AIDS services.

	Strengths	Weaknesses
Confidentiality		
Community Law		
Shame		
Judicial Law		
OH&S		
Pre- & Post-HIV Test Counselling		
Professional Training		
HIV Antibodies Testing Procedures		
Discrimination		
Social Issues		
Employment and Housing Provision		
Professional Concerns		
Community Issues		
Others		





## Appendix 3

### Training and staff development

#### Counselling courses

The regional health training units in each State and Territory can give information about accessing counselling and other training through their system.

Lifeline runs an intensive course that focuses particularly on crisis counselling. Other courses may suit some other areas of your work. Contact the local Lifeline or other similar counselling services.

In NSW, the Albion Street Education Centre releases a calendar of training events through their Education Unit. Access the calendar of events and other information by contacting the Education Unit: Tel: (02) 9332 1090 Fax: (02) 9360 3243

A number of government and community organisations also provide AIDS information, education and counselling services. For more information or pamphlets, check with the local AIDS council.

#### In-house training exercises

The issues relating to HIV/AIDS are complex and challenging. All staff, both paid and unpaid, need time and resources to be able to think through and experience as many different scenarios dealing with living with HIV as possible.

#### HIV/AIDS training material, manuals and guidelines

HIV/AIDS in the Workplace: An Introductory Training Manual, n.d., n.p.

Contains trainers notes, session outcomes, overhead transparency masters and further resource advice presented in a step-by-step user oriented format. \$85, including postage and handling.

The Education Unit Albion Street Centre  
150-154 Albion Street, Surry Hills, NSW 2021  
Tel: (02) 9332 1090 Fax: (02) 9360 3243

AIDS Home Care Handbook

Global Program on AIDS, World Health Organisation, CH 1211, Geneva 27, Switzerland

AIDS Management: An Integrated Approach, n.d., n.p.

Teaching Aids at Low Cost - TALC  
PO Box 49, St Albans, Hertfordshire AL1 4AX, United Kingdom  
Tel: 44 71 275 3869 Fax: 44 71 274 6852

A self care manual Moffatt, B, et al. n.d.,

IBS Press, 2339 28th Street, Santa Monica, CA 90405, USA

Contact Tracing Manual: A Practical Handbook for Health Care Providers Managing People with HIV, Viral Hepatitis, Other STD's and HIV-related Tuberculosis 1997, DHFS, Canberra.

Developed by the Sydney Sexual Health Centre at Sydney Hospital and BB Professional Services.

## Volunteer workers

### Volunteer Information Pack

Developed by ACON (AIDS Council of NSW. The mission Statement for ACON's volunteer service is 'To provide the best possible experience for volunteer's whilst working to end the AIDS crisis'). It is available by contacting (02) 9206 2000

### Community Action on HIV: A Resource Manual for HIV Prevention and Care,

Aboagye-Kwarteng, T. & Moodie, R. (eds) 1995, International Health Unit, Macfarlane Burnet Centre for Medical Research, Australian Agency for International Development, Canberra.  
Tel: (03) 9280 2735 Fax: (03) 9482 3123  
Email: ihu@burnet.mbcmr.unimelb.edu.au

### Evaluating Health Promotion: A Health Workers Guide,

Hawe, P., Degeling, D. & Hall, J. 1990, MacLennan and Petty, Artarmon, NSW.

MacLennan and Petty, 80 Reserve Road, Artarmon, NSW 2064  
Tel: (02) 9669 5755 Fax: (02) 9669 5997

## Appendix 4

### Contacts list

This directory lists people and organisations who can be contacted for information and/or support.

### Contents

- Community organisations
  - peak national bodies
  - AIDS Councils
  - PLWHA groups
  - Positive women's groups
  - Hepatitis C councils
  - referral agencies and resources
- Medical/technical contacts
- Human rights commissions
- State & Territory health departments

### Peak national bodies

#### National Association of People Living With HIV/AIDS (NAPWA)

NAPWA is the peak non-government organisation representing the interests of people with HIV/AIDS at the national level. Major focuses of NAPWA's work are to access treatments and clinical trials, education for PLWHA, care and support and access to services.

NAPWA  
4/74 Wentworth Ave  
SURRY HILLS NSW 2010

PO Box 876  
DARLINGHURST NSW 2010.  
Tel: (02) 9281 1999 Fax: (02) 9212 5344  
Email: [admin@napwa.org.au](mailto:admin@napwa.org.au)  
<http://www.napwa.org.au>

#### Haemophilia Foundation Australia (HFA)

HFA is the peak national body representing State and Territory organisations for people with haemophilia and related bleeding disorders.

HFA  
213 Waverley Rd  
MALVERN EAST VIC 3145.  
Tel: 1800 807 173  
[www.haemophilia.org.au](http://www.haemophilia.org.au)

### Australian Federation of AIDS Organisations (AFAO)

AFAO is the peak body representing the community based, non-governmental response to HIV and AIDS. AFAO undertakes advocacy, policy development and education program coordination at a national level on behalf of its members. AFAO also has a resource directory that is updated to include the latest policy documents pertaining to HIV in Australia. It also includes information from a vast number of organisations providing community-based and government placed services to groups working with people with HIV/AIDS and those affected.

AFAO  
Level 4/74 Wentworth St  
SURRY HILLS NSW 2010

PO Box 876  
DARLINGHURST NSW 1300  
Tel: (02) 9281 1999

National Treatments Project  
Tel: (03) 9865 6700 Fax: (02) 9281 1044  
<http://www.afao.org.au>

### Scarlet Alliance

The National Forum of Sex Workers rights organisations.

PO Box 76  
RED HILL ACT 2603  
Tel: (02) 6239 6098 Fax: (02) 6239 7871  
[scarlet@dynamite.com.au](mailto:scarlet@dynamite.com.au)

### Australian IV League (AIVL)

The national organisation representing education and support groups for injecting drug users.

### AIVL

17 Napier Close  
DEAKIN ACT 2600

PO Box 269  
WODEN ACT 2606  
Tel: (02) 6281 7851 Fax: (02) 6281 7853  
<http://www.taunet.net.au/ntac/aivl/>

## AIDS Councils

AIDS council staff are experienced in matching hospice and respite care services to the needs of families, and are in contact with volunteer services that provide home and other care activities. They also have specific information about housing options for HIV positive people and, in some instances, will be able to organise medium- to long-term housing. They are also a referral point for financial assistance to establish bonds, whitegoods and supported accommodation. They also can provide educational material for those with HIV.

### AIDS Action Council of the ACT (AAACT)

16 Gordon Street  
ACTON ACT 2601

GPO Box 229  
CANBERRA ACT 2601  
Tel: (02) 6257 2855 Fax: (02) 6257 4838  
Information@aidsaction.org.au

### AIDS Council of Central Australia (ACOCA)

119 Todd Street  
ALICE SPRINGS NT 0870

PO Box 910  
ALICE SPRINGS NT 0870  
Tel: (08) 8953 1118 Fax: (08) 8953 4584

### AIDS Council of NSW (ACON)

9 Commonwealth Street  
DARLINGHURST NSW 2010

PO Box 350  
DARLINGHURST NSW 1300  
Tel: (02) 9206 2009 Fax: (02) 9206 2092  
acon@acon.org.au  
www.acon.org.au

### AIDS Council of SA (ACSA)

64 Fullerton Road  
NORWOOD SA 5067

PO Box 907  
KENT TOWN SA 5071  
Tel: (08) 8362 1611 Fax: (08) 8363 1046 TTY: (08) 8362 0306  
acsa@aidsCouncil.org.au

### Northern Territory AIDS Council (NTAC)

6 Manton Street  
DARWIN NT 0800

PO Box 2826  
DARWIN NT 0801  
info@ntac.org.au  
Freecall: 1800 880 899  
Men's line service Freecall: 1800 181 888  
www.ntac.org.au



**Queensland AIDS Council (QUAC)**

32 Peel Street  
SOUTH BRISBANE QLD 4101

PO Box 3142  
SOUTH BRISBANE QLD 4101  
Tel: (07) 3844 1990 Fax: (07) 3844 4206  
info@quac.org.au

**Tasmanian Council of AIDS and Related Diseases (TASCARD)**

2 Brooke Street  
HOBART TAS 7000.  
Tel: (03) 6234 1242 Fax: (03) 6234 1630 Freecall: 1800 005 900

**Victorian AIDS Council/Gay Men's Health Centre (VAC/GMHC)**

6 Claremont Street  
SOUTH YARRA VIC 3141  
Tel: (03) 9865 6700 Fax: (03) 9826 2700  
enquiries@vic aids.asn.au

**Western Australia AIDS Council (WAAC)**

664 Murray Street  
WEST PERTH WA 6005  
Tel: (08) 9429 9900 Fax: (08) 9429 9901

PO Box 1510  
WEST PERTH WA 6872  
waac@wa aids.asn.au

**People Living with HIV and AIDS (PLWHA) groups**

These groups can be contacted for information about support groups, services, social events and outreach programs. Often these organisations distribute newsletters that contain calendars of events, new projects and initiatives, stories, media summaries and treatment updates. Some of these organisations have regional offices.

**ACT Peer Support Network**

PO Box 229  
CANBERRA ACT 2601  
Tel: (02) 6257 4985 Fax: (02) 6257 4838  
plwhaact@hotmail.com

**New South Wales PLWHA NSW**

Level1/94 Oxford Street  
DARLINGHURST NSW 2010

PO Box 831  
DARLINGHURST NSW 2010  
Tel: (02) 9361 6011 Fax: (02) 9360 3504 Freecall: 1800 245 677  
admin@plwha.org.au

PLWHA - NT  
- contact via the NT AIDS Council

**Queensland Queensland Positive People**  
PO Box 3142  
SOUTH BRISBANE QLD 4101  
Tel: (07) 3846 3939 Fax: (07) 3846 1283  
info@quac.org.au

**South Australia PLWHA**  
PO Box 383  
Marleston SA 5033  
Tel: (08) 8293 3700 Fax: (08) 8293 3900 Freecall: 1800 676 708  
plwhasa@camtech.net.au

**Tasmania Positive People**  
GPO Box 595F  
HOBART TAS 7001  
Tel: (03) 6234 1242  
mail@tascard.org.au

**Victoria PLWHA Victoria**  
6 Claremont Street  
SOUTH YARRA VIC 3141  
Tel: (03) 9865 6772 Fax: (03) 9826 2700  
plwhavic@netspace.net.au

**Positive Heterosexuals (NSW)**  
Level 5, Queen Mary Bldg  
Grose St  
CAMPERDOWN NSW 2050  
Tel: (02) 9515 3095 Freecall: 1800 812 404  
dbart@hiv.rpa.cs.nsw.gov.au

**Straight Arrows (Support Group for Heterosexual HIV Positive Men)**  
Alfred Hospital  
Commercial Rd  
PRAHRAN VIC 3181  
Tel: (03) 9276 3792  
straightarrows@bigpond.com

## Positive Women's Groups

Not all States and Territories have support networks for women with HIV. If you cannot find other women with HIV/AIDS in your State/Territory, contact one of the groups listed here.

### Positive Women Victoria (Inc)

PO Box 222  
PRAHRAN VIC 3181

Alfred Hospital  
Commercial Rd  
PRAHRAN VIC 3181  
Tel: (03) 9276 6918 Fax: (03) 9276 6092  
[pos.women@c031.aone.net.au](mailto:pos.women@c031.aone.net.au)

### Positive Women (South Australia)

HIV/AIDS Women's Project  
Tel: (08) 8340 3193

### Positive women (NSW)

Women's Unit  
AIDS Council of NSW  
PO Box 350  
DARLINGHURST NSW 1300  
Tel: (02) 9206 2000  
[acon@acon.org.au](mailto:acon@acon.org.au)

### Positive Women (WA)

Women's Officer  
WA AIDS Council

PO Box 1510  
WEST PERTH WA 6872  
Tel: (08) 9429 9900  
[waac@waaid.asn.au](mailto:waac@waaid.asn.au)

## Hepatitis C Councils

### ACT Hepatitis C Council

PO Box 1067  
DICKSON ACT 2602  
Tel: (02) 6253 9999  
[hepcact@computech.com.au](mailto:hepcact@computech.com.au)

### Hepatitis C Council of NSW

PO Box 432  
DARLINGHURST NSW 1300  
Tel: (02) 9332 1853  
[hccnsw@hepatitisc.org.au](mailto:hccnsw@hepatitisc.org.au)

#### Hepatitis Network NT

GPO Box 36565  
WINNELLIE NT 0821  
Tel: (08) 8981 0708

#### Hepatitis C Council of Queensland

PO Box 179  
Albert St  
BRISBANE QLD 4000  
Tel: (07) 3229 9238  
hepcq@powerup.com.au

#### Hepatitis C Council of SA

PO Box 782  
KENT TOWN SA 5071  
Tel: (08) 8362 8443  
hepsa@senet.com.au

#### Hepatitis C Council of Tasmania

644 Main Rd  
BERRIEDALE TAS 7011  
Tel: (03) 9639 3200

#### Hepatitis C Council of Victoria

Level 9 Carlow House  
289 Flinders lane  
MELBOURNE VIC 3000  
Tel: (03) 9639 3200  
hepcvic@vicnet.net.au

#### Hepatitis C Council of WA

PO Box 8060  
PERTH BUSINESS CENTRE WA 6849  
Tel: (08) 9328 8216  
hepcwa@highway1.com.au

### Medical/technical contacts

#### The Australasian Society for HIV Medicine

ASHM is a medical society comprising doctors, medical scientists, health care professionals and others involved in the field of HIV/AIDS. ASHM aims to inform not only its members but all health care workers. It conducts various meetings and produces publications. ASHM has produced a CD ROM intended for doctors to use in working with clients with HIV, it contains a wide range of information suitable for those with HIV.

ASHM  
150 Albion Street  
SURRY HILLS NSW 2010  
Tel: (02) 9380 9525 Fax: (02) 9380 9528  
ashm@unsw.edu.au

### The Australasian College of Sexual Health Physicians

The College runs a short course in STI medicine. This course is primarily for GPs with an interest in Sexual Health or HIV Medicine.

The Australasian College of Sexual Health Physicians  
Sydney Sexual Health Centre  
GPO Box 1614  
SYDNEY NSW 2001  
Tel: (02) 9382 7457 Fax: (02) 9382 7475

### National Centre in HIV Epidemiology and Clinical Research

This centre runs most of Australia's clinical trials of HIV treatments, and is in charge of keeping the epidemic statistics.

National Centre in HIV Epidemiology and Clinical Research  
Level 2, 376 Victoria Street  
DARLINGHURST NSW 2010  
Tel: (02) 9332 4648 Fax: (02) 9332 1837

### The Community HIV Research Network (CHRN)

Conducts clinical trials within a community setting. This allows access to new compounds by individuals who do not want to attend large hospitals for their care.

Community HIV Research Network (CHRN)  
2nd Floor 376 Victoria Street  
DARLINGHURST NSW 2010

Freecall: 1800 817 763  
Tel: (02) 9331 6320 Fax: (02) 9332 2485

## Referral agencies and resources

### Indigenous Families Council

Is a group of Indigenous individuals, families, friends, workers, carers that are living and dealing with various social and health issues, traumas and situations individuals and families face in everyday life. Confidential and volunteer-based services who work in normalising, referring, and resourcing individuals and families to achieve quality lifestyle management.

Indigenous Families Council  
PO Box 638  
STRAWBERRY HILLS NSW 2010

### The Troy Lovegrove Foundation

The Foundation aims to increase the quality of life of children in Australia who are living with HIV/AIDS. Financial assistance is given to families and children infected and affected with HIV/AIDS. The foundation is also involved in HIV/AIDS education. Support groups can be organised in conjunction with the paediatric units and other HIV organisations.

### The Troy Lovegrove Foundation

PO Box 42  
CARLINGFORD NSW 2118  
Tel/Fax: (02) 9804 6015

## Welfare institutions

There may be assistance in the form of food vouchers, furniture or other domestic items that can be accessed through St Vincent De Paul's, Lifeline, and the Salvation Army. Access to these places in States and Territories can be found in the emergency and welfare sections in the front of local telephone books. More specific information can be found from social workers at HIV clinics and through the AIDS Council in your State or Territory.

## Discrimination

If a person is being discriminated against on grounds of their HIV or AIDS status, there is the possibility that this is against the laws that apply. Some of the larger AIDS Councils operate legal services that can assist, or contact HREOC as follows:

### Human Rights and Equal Opportunity Commission (HREOC)

Federal Legislation:

Tel: (02) 9284 9600

National

State or Territory based legislation:

NSW (02) 9318 5444

Free call 1800 670 812

ACT (02) 6247 3658 (privacy only; not human rights)

SA (08) 8207 1977

TAS (03) 6234 3599

VIC (03) 99281 7111

WA (08) 9264 1930

Community Legal Centres or Aboriginal Legal Services have qualified legal practitioners on hand to answer questions or refer appropriately.

There are lists of legal and advocacy services in the front of the White Pages (Community Help Reference) in each telephone book.

## State, Territory and Commonwealth Territory Health Departments

Northern Territory	(08) 8999 2400
Western Australia	(08) 9222 4222
South Australia	(08) 8226 6000
Victoria	(03) 9616 7777
Tasmania	(03) 6233 8011

New South Wales

(02) 9391 9000

Australian Capital Territory

(02) 6205 5111

Queensland

(07) 3234 0191

Commonwealth

1800 020 103

(02) 6289 1555

## Appendix 5

### Publications

There are many resources available through the AIDS Council in your State or Territory, PLWHA or positive women's/men's groups, which explore issues raised in this booklet in further detail. Some of these include:

### General HIV information

#### ACCESS - A Positive Diagnosis

A pamphlet produced by the National Association of People Living with HIV/AIDS, Inc. (see Contacts List Appendix 4). It is a brief overview of information for people who have been diagnosed positive, and answers several commonly asked questions. Other similar brochures are often produced.

#### Australasian Society of HIV Medicine (ASHM) publications (see Contacts List Appendix 4)

- **HIV Journal Club** - monthly publication reviewing international articles and highlighting important issues for GPs.
- **Noah's Ark** - bi-monthly publication on treatment/management issues and other HIV related topics.
- **Managing HIV** - 1997 Directory of Australasian HIV Medical Services. Lists information about institutions, medical practitioners who provide expert care for people living with HIV, related diseases, State AIDS Councils, etc. It is updated annually.  
Available from: ASHM by membership, subscription or individual request.

#### Communicable Diseases Intelligence

Produced fortnightly by the National Centre for Disease Control of the Commonwealth Department of Health and Aged Care. Contains surveillance statistics and information of interest about communicable diseases in Australia.

#### Complementary and Alternative Therapies: A Guide for people Living with HIV and AIDS (1999 AFAO/NAPWA/ANCARD).

#### HIV/AIDS Surveillance Report

Published quarterly by the National Centre for HIV Epidemiology and Clinical Research (see Contacts List Appendix 4). Contains the very latest surveillance figures, statistics and trends on HIV and AIDS in Australia.

#### HIV/AIDS Legal Link (6 issues per year) (AFAO).

#### HIV/AIDS and Your Rights (1998 AFAO).

#### HIV Drug Book (1998 AFAO).

#### The HIV Herald (6 issues per year) and Positive Living (6 issues per year)

Regular updates on HIV/AIDS treatments and associated issues produced by the National Treatments Project of AFAO (see Contacts List Appendix 4)



## Medical practitioners resources and catalogues

- HIV/AIDS Resources for Registrars
- Medical Educators in the RACGP Vocational Training Program
- Other medical practitioners' catalogues

Developed by the HIV/AIDS Liaison Officer, Royal Australian College of General Practitioners (see Contacts List Appendix 4).

## The National AIDS Bulletin

Bi-monthly journal published by the Australian Federation of AIDS Organisations (AFAO), (see Contacts List Appendix 4). Contains the latest news, information and comment, as well as listings of latest articles and publications on HIV/AIDS issues.

## Royal Australian College of General Practitioners Resource Centre Publications

(see Contacts List Appendix 4)

- Could it be HIV?
- Managing HIV.
- Managing HIV, 1996 Directory of Australian Medical Sources.
- RACGP Sterilisation/Disinfection Guidelines for General Practice.
- National HIV/AIDS Strategy 1996-97 to 1998-99.
- The Indigenous Sexual Health Strategy 1997.
- The AIDS Manual (third edition) A practical handbook on many aspects of HIV infection, including historical, medical, psychological and legal areas, State AIDS information and services list.

## Taking care of Yourself: A Guide for People Living with HIV and AIDS (1999 AFAO/NAPWA).

### Talkabout

Is published by People Living with HIV/AIDS (NSW) Inc. (see Contacts List Appendix 4).

## Venereology - The Interdisciplinary Journal of Sexual Health

Published quarterly by: Venereology Publishing Inc.

Contact: Melbourne Sexual Health Centre, 580 Swanston Street, Carlton VIC 3053  
Tel: (03) 9347 0244 Fax: (03) 9347 2230 Freecall: 1800 032017

## HIV Testing Manual

Alice Springs Remote Health Services 1997, Alice Springs Remote Health Services, Alice Springs, NT.

Available from: The Sexual Health Unit,  
PO Box 721, Alice Springs, NT 0870  
Tel: (08) 8951 7550 Fax: (08) 8951 7555

## HIV Management Plan for Health Services in North Queensland,

Apunipima Cape York Health Council 1998, Apunipima Cape York Health Council, Cairns, Qld.  
Contact: Apunipima Cape York Health Council,  
343 Fearnley St, Manunda,  
PO Box 2797, Cairns, 4870  
Tel: (07) 4051 7450 Fax: (07) 4051 7940

## Procedure, Orientation and Information Manual, rev edn,

Cairns Base Hospital 1997, Cairns Base Hospital, Cairns, Qld.

Available from: Box 902 Cairns Base Hospital, Cairns, 4870  
Tel: (07) 4050 6333 Fax: (07) 4050 6359  
or The Cairns Sexual Health Unit, Phone (07) 4050 3900

**STD Control in Remote Aboriginal Communities: A Manual for Clinic Workers.**

Department of Health and Aged Care (DHAC), Office of Aboriginal and Torres Strait Islander Health 1999, DHAC, Canberra.

Publications Production Unit,  
Commonwealth Department of Health and Aged Care, Canberra

**Testing for HIV Infection: An Information Manual for Clinic Doctors and Nurses on the Anangu Pitjantjatjara Lands.**

Miller, P. 1994, Nganampa Health Council, Alice Springs, NT.

Available from: Nganampa Health Council,  
PO Box 2322, Alice Springs NT 0872

## Websites

**CAPE centre CDC**

A coalition of churches providing outreach in service and education.  
<http://avoca.vicnet.net.au/~capecentre>

**CDC national prevention information network**

A service of the Centers for Disease Control (USA) facilitating the sharing of HIV/AIDS, STI and TB resources and information.  
<http://www.cdcnpin.org>

**Communication initiative**

Planning and strategies methods, communication, behaviour change methods in developed and developing countries, evaluation, development issues, partnerships, communication trends.  
<http://www.comminit.com>

**HIV InSite**

Comprehensive site: medical, prevention, social issues, resources. Clinical information and trials. Prevention and education.  
<http://hivinsite.ucsf.edu>

**HIV Positive**

For HIV positive people.  
<http://www.hivpositive.com>

**HIV web library**

An online library containing HIV and AIDS related information  
<http://www.infoweb.org>

**Roche HIV**

Fostering understanding of the HIV virus and treatment issues.  
<http://www.roche-hiv.com>

**SEA-AIDS**

The information support service for people living or working in the Asia-Pacific region.  
<http://unaidsapict.inet.co.th/>

**The Body**

A HIV/AIDS information resource with a focus on the needs of people living with HIV/AIDS, a community based site.  
<http://thebody.com>

## UNAIDS

UNAIDS supports the global response to HIV, contains the best practice collection technical and advocacy materials.  
<http://www.unaids.org>

## Victorian AIDS Council centre clinic

HIV and AIDS information, safe sex and HIV, prevention, HIV testing, HIV treatments, information for HIV positive people, complementary therapies, links page for HIV information.  
<http://www.vicaids.asn.au>

Commonwealth Department of Health and Aged Care  
<http://www.health.gov.au>

## Program planning and evaluation

### Partners in Evaluation: Evaluating Development and Community Programmes with Participants Feuerstein,

M.T. 1986, Macmillan Education, Hong Kong.

Teaching AIDS at Low Cost (TALC)  
PO Box 49 St. Albans, Hertfordshire, United Kingdom.  
Tel: (44) 727 53869 Fax:(44) 727 46852

### Project Identification, Design and Appraisal: A Manual For NGOs

Zivetz, L. 1990., Australian Council for Overseas Aid, Canberra.

The Appraisal and Evaluation Unit,  
Australian Council for Overseas Aid  
PO Box 1562 Canberra, ACT, Australia 2601.  
Tel: (02) 6285 1816 Fax: (02) 6285 1720

### Evaluating HIV/AIDS Prevention Programs in Community Based Organisations,

National Community AIDS Partnership, n.d., National Community AIDS Partnership,  
Washington, DC.

A guide designed to assist program designers, managers and funders in the selection of an appropriate evaluation methodology for their program.

National Community AIDS Partnership  
1140 Connecticut Avenue, NW Suite 901,  
Washington DC, 20036-4001 USA  
Tel: (1 202) 429 2820 Fax: (1 202) 429 2814

### Everyday Evaluation on the Run

Wadsworth, Yoland 1991, Action Research Issues Association, Melbourne, Vic.

Action Research Issues Association (Incorporated)  
Fourth Floor 247 - 251 Flinders Lane, Melbourne, Vic. 3000  
Tel: (03) 9650 6963

## HIV/AIDS publications

Almond, B. (ed) 1990, AIDS - A Moral Issue: The Ethical, Legal and Social Aspects, Macmillan, Basingstoke, UK.

Augustsson, Cheryl (comp) 1996, AIDS Sickness: Information for Yamatjis, Gascoyne Public Health Unit, Carnarvon, WA.

Augustsson, Cheryl (comp) n.d., HIV/AIDS - 'AIDS Sickness' Are you at risk? Gascoyne Public Health Unit, Carnarvon, WA.

Produced by the Gascoyne Public Health Unit  
Cnr Cleaver and Johnson Street  
Carnarvon, WA 6701.

(These two booklets produced for and by local Yamatjis in the Gascoyne region of Western Australia.)

Bere, M. & Ray, S. 1993, Women and HIV/AIDS: An International Resource Book, Pandora Press, Hammersmith UK.

Pandora Press  
77 Fulham Palace Road Hammersmith W6 8JB UK

Brown, K. C. & Turner, J. G. 1989, AIDS: Policies and Programmes for the Workplace, Van Nostrand Rienhold, New York, NY.

Frontliners, 1987, Living with AIDS: A Guide to Survival by People with AIDS, Terrence Higgins Trust, London.

The Hidden Costs of AIDS: The Challenge of HIV to Development 1992, Panos Institute, London.

Panos Institute  
9 White Lion Street, London N1 9PD UK.  
Tel: (44) 71 278 1111 Fax: (44) 71 278 0345.

Issues of HIV Testing in Developing Countries, 1992, UK NGO AIDS Consortium, London.

UK NGO AIDS Consortium  
Fenner Brockway House  
37-39 Great Guildford Street London SE1 0ES, UK  
Tel: (44) 71 401 8231 Fax: (44) 71 401 2124

Kubler Ross, E. 1987, AIDS: The Ultimate Challenge, Macmillan, New York, NY.

Miller, D. 1987, Living with AIDS and HIV, Macmillan, London.

O. Shaughnessy, T. 1994, Beyond the Fragments: HIV/AIDS and Poverty, World Vision Australia, Burwood East, Vic.

World Vision Australia,  
1 Vision Drive, Burwood East, Vic, 3151  
Tel: (03) 9287 2233 Nat Office: 13 3240

Radlett, M. 1989, AIDS and Children: A Family Disease, Panos Institute, London.

Panos Institute  
9 White Lion Street London N1 9PD UK.  
Tel: (44) 71 278 1111 Fax: (44) 71 278 0345

Rieder, I. & Ruppelt, P. (eds) 1989, *Matters of Life and Death: Women Speak about AIDS*, Virago Press, London UK.

Squire, C. 1993, *Women and AIDS: Psychological Perspectives*, Sage Publications, London.

Sage Publications  
6 Bonhill Street London EC2A 4PU UK

Timewell, E., Minichiello, V. & Plummer, D. 1992, *AIDS in Australia*, Prentice Hall, Sydney, NSW.

Prentice Hall  
PO Box 151 Brookdale, NSW 2100.  
Tel: (02) 939 1333 Fax: (02) 938 6826.

UNICEF 1992, *Children and AIDS: An Impending Calamity*, UNICEF, New York, NY.

UNICEF  
3 United Nations Plaza  
New York, NY 10017 USA.  
Tel:(1 212) 326 7000 Fax:(1 212) 888 7466.

Wolfer, Ivan 1992, *AIDS and Primary Health Care: The role of non-Government Organisations*, VU University Press, Amsterdam.

VU University Press, De Boelelaan 1105, 1081 HV,  
Amsterdam, The Netherlands.  
Tel: (31) 20 644 4355 Fax: (31) 20 646 2719.

World Health Organisation 1991, *Facing Sensitive Issues: AIDS Prevention Through Health Promotion*, WHO, Geneva.

WHO Distribution and Sales  
CH 1211 Geneva 27 Switzerland.  
Tel: (41) 22 791 2111 Fax: (41) 22 791 0746.

### Strategies for Hope Series

Campbell, I. D. & Williams, G. 1990, *AIDS Management: An integrated Approach*, Strategies of Hope Series no. 3, ActionAID, London.

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## Appendix 6

### Financial assistance and Centrelink services

#### Financial assistance and counselling

Some of the AIDS Councils operate a financial assistance program for people with HIV/AIDS. Most of the AIDS Councils are able to refer to financial counsellors who are experienced at assisting people with HIV/AIDS in managing finances and debts. Contact the AIDS Council in your State or Territory to find if they have such a program and for eligibility criteria. Contact details are in appendix 4.

#### Centrelink

There are a number of Centrelink payments available to people who are currently unable to participate in the workforce. Centrelink offers a Community Services Unit. If a client is too sick to access a Centrelink office a home visit can be arranged.

Further information regarding Centrelink payments and services can be found in the Centrelink booklet Help for people affected by HIV/AIDS.

For all enquiries call your Centrelink Service and make an appointment on 131021.

Calls can be made from anywhere in Australia for the cost of a local call.

Centrelink has a commitment to ensure the privacy and confidentiality of its customers.

#### Special services in Centrelink

##### Aboriginal and Torres Strait Islander Liaison Officers

Ask for the Aboriginal and Torres Strait Islander Liaison Officer at the Centrelink office to assist with an application if necessary.

##### Disability Support Officers

Disability Support Officers (DSO) are specialist officers who provide advice to Centrelink staff about entitlements to disability payments and who make complex decisions on eligibility for Disability Support Pension and, in some cases, Sickness Allowance.

Disability Support Officers also help identify people who may benefit from training, rehabilitation or job search assistance. Ask for the DSO at the Centrelink Office.

##### Social Workers

Every Centrelink office has at least one Social Worker. Social Workers can help with personal matters by providing counselling, information and advice. They can liaise with community support agencies and can also refer to other departments, agencies or organisations for further assistance. Social Workers can come to visit at home if a client is unable to attend the office.

### Field Assessors

Once Centrelink payments start they are reviewed on a regular basis, usually by mail. If too sick to attend the office, a field assessor will visit at home. All departmental staff are issued with individual identification cards with name and photographs and must show the card before entering a home.

### Financial Information Service

Centrelink has a Financial Information Service (FIS) which can help current and potential clients use their own money to best advantage. The service is confidential and free. Contact the Centrelink Office or phone 131021 to make an appointment with the nearest FIS officer.

### Newstart Allowance

People on Newstart allowance who are temporarily unable to work do not transfer to Sickness Allowance but instead remain on Newstart. A medical certificate is required for a person to be exempted from looking for work for the duration of the certificate. It may still be necessary to lodge fortnightly forms.

For all enquiries call your local Centrelink Service and make an appointment on 13 10 21.

Calls can be made from anywhere in Australia for the cost of a local call. Centrelink has a commitment to ensure the privacy and confidentiality of its customers.

If you have any concerns about your privacy being threatened contact:  
The Privacy Hotline on 1800 023 985.

### Sickness Allowance

People who are temporarily unable to work or study due to illness or injury and who have experienced a loss of income may be eligible for sickness allowance. A medical certificate must be provided by a registered medical practitioner. Payment under this allowance finishes when the medical certificate expires. It is therefore important to organise another certificate in advance to avoid payment being stopped. Sickness Allowance is not a long-term payment. There is an expectation sick leave is already taken before accessing this payment.

### Disability Support Pension

The Disability Support Pension is available to clients who are unable to work full time or for long periods. A medical report is necessary and an examination by a Health Services Australia Medical Assessor may be required, depending on the information contained in the medical report.

### Carers Pension

The Carer's pension is available to people providing full-time personal care for an adult with acute HIV infection or in the later stages of the virus.

Sickness Allowance, Disability Support Pension and Carer's Pension are all subject to income and asset tests.

### Mobility Allowance

This allowance is available to provide assistance to people with disabilities who are in employment, vocational training, a combination of work and training, voluntary work, and who are unable to use public transport without substantial assistance. A medical report should be provided and evidence about being currently employed, training or participating in voluntary work.

### Rent Assistance

Rent assistance will be paid as an addition to the pension, benefit or allowance for people on some form of social security payment who are renting privately.

## Glossary of terms

### Acquired Immune Deficiency Syndrome (AIDS)

A complex set of clinical conditions in which the body's immune system is seriously damaged by HIV infection and therefore becomes vulnerable to opportunistic illness.

### AIDS council

A community based, non-government organisation established to provide education, support and care for people infected with HIV or at risk of infection.

### ANCARD and ANCAHRD

Australian National Council on AIDS and Related Diseases. The advisory body to the Commonwealth with regard to HIV/AIDS, Hepatitides and Sexual Health. Australian National Council on AIDS, Hepatitis and Related Diseases replaced ANCARD in 1999 to better reflect its role.

### Antibody

A chemical substance specifically produced in the body by the immune system to attack a corresponding substance that is foreign to the body. A person living with HIV produces HIV antibodies in a vain attempt to kill the virus. The presence of these antibodies in the body indicates that a person is HIV positive.

### Antibody positive

People who have been exposed to HIV and who have developed antibodies to the virus are said to be antibody positive, or seropositive.

### Antiretroviral Prescriber

HIV/AIDS antiretroviral drugs are funded by the Highly Specialised Drugs Program which a National program and an adjunct to the Pharmaceutical Benefits Scheme. Drugs are prescribed by a HIV/AIDS specialists or appropriately accredited General Practitioner. All prescribers must have a link to either a private or public hospital, which specialises in the treatment of HIV/AIDS. The prescribing protocols are a National standard and do not differ between States or locality. The only difference in the program is that the Commonwealth has agreed to allow individual States and Territories the flexibility to train and accredit their own General Practitioners.

There is no current proposal to vary the way in which these drugs are made available to Australians in contrast to the proposals to make other pharmaceutical benefits available in remote Aboriginal communities through more relaxed practices

### Antiviral

The most common group of anti-HIV drugs which slow disease progression by interfering with the way the virus replicates.

### Asymptomatic

A phase of an infection without symptoms. Many people with HIV remain asymptomatic for years.

### AZT

Also known as zidovudine, AZT is the most commonly used anti-HIV drug.

### CD4 cells

(see T4 cells).

### Combination therapy

The use of two or more types of treatment in combination to increase the effect of intervention.



## Early intervention

The interruption of the progress of a disease at an early stage of infection to prevent the onset of illness.

## Haemophilia

Hereditary blood disorder that prevents blood clotting. Many people with haemophilia in Australia were infected with HIV through contaminated blood prior to the introduction of blood screening in 1985.

## HIV/AIDS

Refers to both Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome.

## HIV antibody test

A set of blood tests used to determine whether a person is HIV positive or HIV negative. It tests for antibodies to HIV, produced by the body's immune system.

## HIV infection

State of being infected with HIV.

## HIV negative

People who have not developed antibodies to HIV are HIV negative. However, a negative test does not mean that an individual is HIV free, as it may take from two weeks to three months after exposure to the virus to develop antibodies.

## Human Immunodeficiency Virus (HIV)

A human retrovirus that leads to AIDS. May be referred to as HIV, HIV virus or HIV infection. At least three different strains of HIV have been identified, but the most common in Australia is HIV1. HIV2 is very common in Africa but fewer than 10 people have been diagnosed in Australia with this strain of HIV. HIV0 is a newly described strain about which very little is known. The important issue is that all three will lead to AIDS and are distinguishable only by very sophisticated tests.

Preliminary research suggests, however, there may be some differences between the strains in the length of time it takes for a person who is HIV positive to progress to AIDS. In the case of HIV1 the timeline is usually between 10 and 15 years. Blood for blood banks in Australia are routinely screened for HIV1 and HIV2.

## Immune system

The body's mechanisms to resist infection and disease. Lymphocytes, a class of white blood cells, recognise and destroy foreign substances (called antigens). HIV infection results in the depletion of a subset of T-cells (CD4-cells) and this results in immunodeficiency.

## Indigenous Australians Sexual Health Working Party

Sub-committee of ANCARD to advise on Indigenous Issues. In 1999, the Indigenous Australians Sexual Health Committee was formed under the new structure of ANCAHRD.

## Incidence

An epidemiological term which describes the number of new cases of a disease during a specific period.

## Injecting drug user

A term used to describe someone who injects drugs, whether into the skin, vein or muscle.

## Lymphocytes

A type of white blood cell that recognises and fights infection. B-cell lymphocytes produce antibodies, and T-lymphocytes activate and control the cellular immune system in response to foreign substances, particularly viruses.

## Opportunistic illness

Infection or tumour that occurs because the damaged immune system cannot fight it off. Such illnesses do not generally occur in people with intact immune systems.

## p24 antigen

A marker of HIV reproduction that is measured in the blood. The antigen p24 is a protein fragment of HIV.

## Prevalence

An epidemiological term which refers to the number of persons in a given population with a disease at a specified time. Prevalence counts already existing cases as well as new cases.

## Prophylaxis

Treatment intended to prevent an infection or disease; for example, condoms prevent infection.

## Resistance

Diminished effectiveness of drug against its target resulting from the ability of the target to mutate.

## Retrovirus

A class of virus, including HIV. Retroviruses do not have DNA, the molecule that contains genetic information that cells use to reproduce themselves. Instead, retroviruses have RNA, and use an enzyme called reverse transcriptase to transform RNA into DNA.

## Safe sex

Sexual activity carried out where there is no exchange of body fluids such as semen, vaginal fluids or blood.

## Seroconversion

This process occurs when someone has been in contact with HIV and becomes infected. Seroconversion may be accompanied by an illness similar to glandular fever.

## Seropositive

A set of blood test (ELISA, Western blot) results indicating a person has antibodies to HIV (see HIV positive).

## T4 cells

A group of white blood cells (T-lymphocytes) that protects the body against invading organisms. In people with advanced HIV disease or AIDS, T4 cells become depleted to a point where they are ineffective, thereby allowing opportunistic infections to occur.

## Viral load test

Quantitative test for the amount of virus present used particularly during the diagnosis and treatment of HIV/AIDS; for example, to ascertain the efficacy of antiretroviral treatment.

## Virus

Any large group of microscopic agents dependent on living cells for reproduction and lacking independent metabolism.

## Window period

A length of time in which a person is infected with HIV, but has not produced sufficient antibodies to be detected by a HIV antibody test; i.e. they would not produce a HIV positive test result although they are infected. The window period averages about three months.



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