

taking care of yourself

a guide for people with HIV/AIDS

second edition 2003

staying well
quality of life
taking care

TAKING CARE OF YOURSELF
HIV

TABLE OF CONTENTS

CHAPTER 1	
YOU & HIV/AIDS — WHAT TO EXPECT	1
CHAPTER 2	
LOOKING AFTER YOURSELF — GETTING SOME SUPPORT	4
CHAPTER 3	
MONITORING YOUR HEALTH	16
CHAPTER 4	
WORKING WITH YOUR GENERAL PRACTITIONER	21
CHAPTER 5	
THE TREATMENTS MAZE	27
CHAPTER 6	
COMPLEMENTARY THERAPIES	39
CHAPTER 7	
NEUROLOGICAL AND PSYCHOLOGICAL COMPLICATIONS OF HIV	43
CHAPTER 8	
COMMUNITY CARE AND SUPPORT	51
CHAPTER 9	
GOING TO HOSPITAL	56
CHAPTER 10	
HOSPICE AND PALLIATIVE CARE	69
CHAPTER 11	
BEING INVOLVED IN RESEARCH AND CLINICAL TRIALS	73
ORGANISATIONS AND GROUPS THROUGHOUT AUSTRALIA	79



napwa



ISBN 1 876469 08 0

© Second Edition AFAO/NAPWA Reprinted 2003

Written by Lou McCallum, McCallum & Young Consultants, Sydney

Additional material by Dr Ron McCoy

Additional material (2003 edition) by Kirsty Machon

Thanks to: Dr Mark Newell; Dr Nick Medland

Designed and produced by City Design & Production Pty Ltd • Sydney

YOU & HIV/AIDS - WHAT TO EXPECT

what to expect

What you'll find in this book

This is a guide to a range of health and lifestyle issues and questions for people living with HIV and AIDS. It contains some information about things which may affect your day to day life now or at some time in the future as a person living with HIV or AIDS.

taking control
better health
identities lifestyles

The information in this book is meant to provide a fairly general overview of your options, what you might expect as a positive person, and to introduce you to the range of medical and non-medical care and support services available. It will also explain to you the standards of care and service that you can expect from HIV/AIDS organisations, community health organisations, and your medical practitioners.

You're likely to have some much more specific questions about some of the issues discussed in this book which will not necessarily be answered here. However, more specific resources are available from your local AIDS councils, in print and on the internet, which cover some of these topics in much more detail. There are resources available on:

- tests and treatments for HIV;
- women and HIV;
- complementary therapies for HIV;
- issues for injecting drug users;
- travel within Australia and overseas;
- your legal rights;
- opportunistic infections;
- sex and HIV positive gay men.



If you contact the AIDS council in your state, or talk to your general practitioner, you can find out more about these specific resources, and other sources of information.

Who is this book for?

The information in this book is meant to be broadly relevant to all people living with HIV and AIDS. You may be newly diagnosed and wondering what to expect, or what services are available for you. You may have been HIV positive for some time, and for the first time thinking about treatments, your emotional wellbeing, complementary therapies, or entering the hospital system.

It's hard to generalise about the experience of living with HIV/AIDS. As treatment changes, and the epidemic changes, no one person's experience of HIV or AIDS is going to be the same as anyone else's. We have tried to use examples which will reflect the needs and experience of men, women, children and young people. We have also endeavoured to make this book accessible no matter what your lifestyle or identity.

Every person seems to have a different experience of HIV/AIDS. Some people with HIV are sick from the very beginning whilst others seem to go for years without any discomfort or illness. Developments in HIV/AIDS treatments have dramatically changed the way people experience HIV/AIDS with many people experiencing long periods of better health. However, with the wider use of HIV drugs, drug side effects have become a major issue for some people, and treatment patterns are also changing to reflect this. The experience of people with HIV/AIDS also depends on some very individual factors. HIV/AIDS can affect men and women in different ways. Children and young people with HIV/AIDS also have a different pattern of illness. People with pre-existing conditions like haemophilia can also experience HIV/AIDS differently.

You will probably find that there are times when you are sick and focused almost entirely on HIV/AIDS and other times when you are well and your HIV infection seems to fade into the background.

It might take some time before you can see what your experience of HIV/AIDS is going to be. Other people with HIV are often a great source of support, but remember also that their experiences might be quite different from your own. Everyone has their own set of reactions, infections, illnesses, struggles and achievements.

All sorts of people will try to give you advice. You'll be told things like:

- you've got to get it into perspective;
- just accept it – we have;
- live every day as it comes;
- try not to think too much about it;
- just try to relax;
- you've got to look after yourself;
- remember not to put anyone else at risk;
- you've got to take a positive attitude;
- you've got to be a Person Living with HIV/AIDS, not a victim;
- you've got to empower yourself and take control.

It's pretty hard to do all these things at once. The reality is that HIV can be a bit of a roller coaster ride. There are lots of ups and downs, times when you forget about it, times when you think of nothing else, times when it seems to dominate you, times when you seem to be on top of things.

Finding a way to maintain some level of peace of mind and control through all this is probably the biggest challenge of HIV/AIDS. The only sensible thing to assume is that it will be unpredictable and that the best asset you can have is the flexibility to respond to the changes that you experience.

That makes it sound like you will be totally out of control — that's not true either. What you may need to do is develop the skill and calm to assess each situation as it occurs and to ask for the help you need at each point along the way. This book sets out some of the strategies which you can use to help you look after yourself and tells you what you can expect from the services which are available.



GETTING SOME SUPPORT, ADVICE AND ASSISTANCE

getting some support,
advice and assistance

assistance
peer support
Counselling
information

There are lots

of ways to take care of yourself and to get support. You don't have to use all of these at once. There will be times when you need more support and times when you don't. Don't be afraid to shop around.

Peer support – how do other people with HIV/AIDS manage?

One of the most remarkable aspects of the response to HIV/AIDS in Australia has been the degree to which people with HIV, their carers and friends have grouped together and provided each other with support, encouragement and information. Most states and territories have a PLWHA (people living with HIV/AIDS) association which operates either as part of the AIDS council or as a separate body. PLWHA organisations and AIDS councils have provided peer support groups for people with HIV and these groups have led to the establishment of a supportive network of people with HIV/AIDS. The national umbrella group for this is the National Association of People Living with HIV/AIDS (NAPWA).

Peer support means the support for people with HIV/AIDS is provided by men and women with HIV/AIDS. The advantage of this kind of support is that you know that the person you are talking to has some understanding of the things that you are experiencing and may have already dealt with some of the things you are dealing with.

If you are a gay man with HIV/AIDS, peer support groups will bring you into contact with other gay men with HIV/AIDS. For women with HIV/AIDS it can be a bit harder to get peer support as the number of women with HIV/AIDS in Australia is relatively low. There are some women's groups in some capital cities. Your local PLWHA organisation can generally help connect you with other people who have HIV/AIDS. If you are a heterosexual man with HIV/AIDS in Australia, you may also find peer support harder to access because of the relatively low numbers of positive straight men. In some states, there are specific services for heterosexuals with HIV.

State and territory based injecting drug user organisations will generally be able to connect you with other people with HIV if you are a former or current injecting drug user. There are also hepatitis C services across Australia for people who are also positive to this virus. If you have haemophilia and HIV/AIDS, there is usually support available through the haemophilia services.

The telephone numbers for many of these groups and organisations are at the back of this book.

Identity is a complicated thing. Peer support means getting support from, and giving support to, someone you consider to be having a similar experience to yours. You may have several different identities: man with HIV/AIDS, Asian man, gay man, young man; woman with HIV/AIDS, young woman, mother; man with HIV/AIDS injecting drug user, heterosexual man. It's up to you to decide who are your peers and how to get support.

What sorts of things get discussed at HIV peer support groups?

- Disclosing your HIV status — who, how, when, why
- Sex and HIV/AIDS
- How to get good information and advice about treatments
- Acceptance of your choice to go onto treatments or not
- Tips for staying healthy and positive
- How to deal with anger and stress
- Grief and loss
- How to deal with depression and isolation



- Relationships
- What other support services are available

Peer support isn't for everyone. Some people with HIV/AIDS do not have an interest in meeting other positive people for support. Some prefer counselling and support provided by people who do not have HIV/AIDS.

Peer support groups usually run once a week for six to eight weeks and have a program which includes guest speakers on relevant issues and sessions devoted to a discussion of particular issues. They are generally run by one or two HIV positive facilitators who are trained to make sure that the group runs smoothly.

The participants usually agree on a set of rules or understandings at the beginning of the group. These might include:

- maintaining each other's privacy outside the group;
- respecting the rights of the other people in the group to have their own opinions;
- that they will let each person speak;
- that they will try to concentrate on talking about their own thoughts and feelings and not challenge the things that other people in the group say;
- that people don't come to the group immediately after using drugs or alcohol.

These rules or understandings help to make sure that the people in the group can feel comfortable talking about the things which are important to them.

What can you expect from an HIV peer support group?

- Support
- Accurate information
- A sense that you are not alone
- Confidentiality
- A non-judgemental environment
- Group leaders who are trained and supported by the organisation providing the service

- **Accountability:** that the organisation takes responsibility for providing a high-quality service

Some support groups include men and women with HIV/AIDS. Others are specifically for women, for gay men or for heterosexual men. You need to think about what sort of group you would prefer and seek that out.

Being part of a PLWHA Organisation

Some people with HIV/AIDS join a PLWHA organisation as well as or instead of a peer support group. These organisations advocate on behalf of people with HIV/AIDS and provide information for people with HIV/AIDS on treatments and lifestyle issues.

PLWHA organisations are run by people with HIV/AIDS and provide an opportunity for people with HIV/AIDS to work together on issues which are important to them. PLWHA organisations also draw on the skills and experience of people from the communities affected by HIV and some people who do not have HIV/AIDS also work as staff and volunteers in these organisations.

This movement of people with HIV has been a very effective one. It works to make sure that people with HIV get access to high quality services, free from discrimination and stigma. Joining a PLWHA organisation not only provides you with a way of helping other people with HIV and participating in a global movement, it also provides a place for you to get support, encouragement and information.

Some prefer this method of getting support because the support you get is a spin-off of your involvement in the organisation. Others like to separate their advocacy or community activities in HIV/AIDS from the way in which they get personal support. It's really up to you. People with HIV/AIDS certainly get support from each other as a part of their involvement in these organisations.

There are lots of things to do in PLWHA organisations. You could help with the newsletter, magazine or other publications. You could



represent the organisation on committees or on the boards or working groups of other organisations like AIDS councils. You could help investigate treatments or lifestyle issues and prepare information materials. You could be involved in community education, giving talks as a person with HIV to help break down stigma and discrimination or you could help maintain the office. You can set your own limits on how involved you get and at what level.

If you haven't got time to be involved in the organisation, you can still become a member and get access to newsletters, information about HIV/AIDS treatments and services, information sessions and social events.

Counselling

HIV/AIDS presents many challenges. Many people with HIV/AIDS use counselling as a way to develop the skills and insights they need to maintain a positive approach and to keep their HIV/AIDS diagnosis in perspective.

You don't have to be in a crisis to seek counselling. Counselling is usually designed to help you sort through your feelings, identify coping strategies and find ways to move forward. A counsellor can provide a neutral sounding board for you to express your feelings, fears and ideas. Getting some counselling before you get into a crisis can sometimes prevent the crisis from happening. Having a counsellor can also mean that you enjoy your time with your friends, family and partner more as you get to sound off, complain and talk about your feelings in your counselling session instead of with your friends. This can make the time you spend with your family and friends more enjoyable.

It is important to shop around for a counsellor whose approach matches what you want from a counsellor. To do this, you could ask around. Ask your GP, AIDS council, PLWHA group, or social worker for recommendations or descriptions of the different approaches. You can also usually arrange for a 'test visit' with a counsellor to talk about how they work and to see if it is what you want.

Free counselling is often available through AIDS councils, sexual health centres or hospitals.

How do you know if you need a counsellor?

- There may be no way of knowing: it may just be worth a try anyway.
- You may be angry and irritable all the time or more than usual.
- You may have a head full of thoughts and feelings and no-one to tell them to.
- You may be shutting yourself away, spending more and more time alone, feeling unmotivated and tired all the time.
- Your drug and/or alcohol intake may be rising.
- You may be having thoughts and feelings that disturb you.
- People you trust might be telling you that you need to get some support.

Counselling can be one-to-one or in groups. It's usually carried out by a trained professional who is bound by a code of practice — either a social worker, a psychologist or a person with specific training in a particular counselling approach.

There are many different counselling techniques and approaches. Some counsellors have a particular approach or set of techniques. Others are more general and use a combination of approaches. Some focus on letting you do most of the talking and see their role as being a sounding-board or listener. Others are more interactive and work with you to find ways to reduce your stress and increase your sense of control. All these techniques have their own value. It really depends on what you want and how you want to work with the counsellor.

Things to think about when choosing a counsellor:

- Do I want someone who will just let me talk and not challenge what I say?
- Do I want someone to analyse my thoughts and feelings?
- Do I want someone who will teach me new skills to help me cope?



- Would I be more comfortable with a man or a woman?
- Can I afford to pay or do I look for a free counsellor?
- How much time do I want to invest in counselling?
- Do I have specific things I want to deal with in counselling?
- What do I expect to achieve from counselling?

Some questions to ask the counsellor on your first visit or when making an inquiry about their service:

- Do you see other people with HIV/AIDS?
- How is my confidentiality protected?
- How do you work? What approaches do you use?
- Do you charge?

AIDS treatments information

HIV/AIDS treatment is a continually evolving area. Treatments can seem so daunting and the information so highly technical you might be tempted just to leave it all up to your doctor. But there are services available which track the development in HIV treatments and translate complicated information into plain English. It's probably wise to have more than one source of treatments information, as by relying on a single source you may miss an important development.

Having your own source of treatments information can improve your relationship with your doctor, as it means that you can participate more in making decisions about whether to have treatments or not, what treatments to have, when to start and stop them and so on. There are several ways to keep yourself up to date with these developments.

Your local AIDS council or PLWHA organisation will probably have a treatments officer or treatments information project. The treatments officer has the task of keeping track of developments in HIV/AIDS treatments and giving people with HIV/AIDS information to help them make decisions about treatments.

Positive Living is a magazine for HIV positive people published every two months by the National Association of People Living with HIV/AIDS. It is available as an insert published in local lesbian and gay media in each state, on the Internet, or you can also have it mailed to you free of charge each issue.

Your GP may also receive treatments updates from a variety of sources and can pass them on to you.

There are lots of Internet sites which are regularly updated. Finding HIV/AIDS information on the Internet can be extremely helpful, but you need to be especially careful that the information you are getting is correct. Many fallacies and myths, some of them very dangerous, are published on the internet about HIV, particularly (but not only) in relation to complementary therapies.

Signs of a reliable web site might be:

- information is provided in clear, factual, plain English;
- there are doctors or professional medical bodies associated with the web site eg. as authors, commentators or site sponsors;
- it has a simple, easy-to-use search engine;
- it has links to other well-established consumer, government or medical bodies;
- claims about treatments and therapies are verified and source material is referenced or clearly described;
- the information appears balanced and fair (eg. there are no outrageous or suspicious claims made about the effects of particular treatments, like that it can 'cure' HIV or cancer).

The following is a list of web sites you might find helpful. Bear in mind also that some treatments available in the US or Europe may not yet be licensed here, or available only in trials or on special access. Other information (legal and policy information) may also be quite different.



- ▶ Australian Federation of AIDS Organisations (AFAO)
<http://www.afao.org.au>

Treatments information, education, policy and prevention info, links to some other organisations

- ▶ National Association of People Living with HIV/AIDS (NAPWA)
<http://www.napwa.org.au>

Treatments information, policy and discussion papers, information about living with HIV/AIDS, links to/info about some local HIV/AIDS support services

- ▶ Aidsmap (United Kingdom)
<http://www.aidsmap.com>

Extensive range of information about HIV and its treatment

- ▶ The Body (United States)
<http://www.thebody.com>

Information about living with HIV/AIDS, discussion forums, links and more

- ▶ Medscape
<http://www.medscape.com>

International medical information web site (free to join) with extensive information about HIV and other health issues targeted mostly at doctors and clinicians, but topical and usually accessible. Conference coverage.

Diet and exercise

Eating well and getting some exercise will put you in a better position to respond both physically and emotionally to HIV/AIDS. It's easy to say that you should eat well and get some exercise but it's sometimes hard to do. The treatments you take might have side effects which affect your appetite and sense of taste. You may feel tired a lot and exercise might be the last thing you want to think about.

Diet and exercise can also be useful to help manage some of the side effects you might experience from your HIV treatments, like diarrhoea, changes to your blood fat or cholesterol levels, or physical body shape changes like fat loss or gain.

There are dietitians that work in hospitals and clinics who can help you find ways to maintain a properly balanced diet. If you are having problems eating, or if you have chronic diarrhoea, find out from your doctor or AIDS council if there is a dietitian available to give you some assistance.

You can also get nutritional information and advice from your GP, local AIDS council or PLWHA organisation. AIDS councils may also have services which provide cheap vitamins and information on maintaining good nutrition on a low income.

If you are admitted to hospital for a period of time, ask to see the dietitian so that you can work out a nutrition plan to make sure that you get the food that you need.

You can also get some advice on exercise from a physiotherapist. In some cities there are gyms which offer special exercise sessions for people with HIV/AIDS. If there isn't a specialised service in your area, try to get some regular exercise that doesn't put too much strain on your system — walking, swimming or doing light weights are good for this.

A little exercise every day is better than a burst of enthusiasm followed by three weeks on the couch!



Assistance with housing, finances, benefits, legal issues

Living with HIV/AIDS can be an expensive business. It can cost a lot of money to take care of yourself and you may, at some stage, not be able to maintain consistent employment. Even if you are working, the costs of maintaining your health can be a burden.

It is sometimes hard to ask for help in this area. People sometimes feel that they have failed in some way if they need financial support. Try to remember that many of these services were set up by the affected communities to help community members. Even if you feel uncomfortable having to use these services, you should be able to expect that you will be treated with dignity and respect and that the people in these organisations will be keen to make you feel comfortable.

There are lots of services available to help you if you need advice or assistance. Some of these are:

- your state/territory Department of Housing may have a scheme which can either place you in a Housing Department property or subsidise your rent in a privately rented house or flat;
- Centrelink has a range of benefits which apply to people with HIV/AIDS;
- AIDS charities (like Bobby Goldsmith Foundation in NSW) or financial assistance schemes in many states and territories which can help you to purchase household goods or to pay regular bills: these schemes are usually based in or near your state/territory AIDS council; and
- mainstream charities and organisations like the Salvation Army, St. Vincent de Paul.

There may be other services in your area that can help you to manage your finances (eg. Positive Employment Service in NSW). There may be a free legal service at your state AIDS council or, if not, you may be able to get free legal advice from a community legal centre.

If you are having trouble finding the help you need, or if you feel uncomfortable making use of these services, counsellors or HIV support staff at your local AIDS Council can help you get what you need.

What can you expect from these support services?

- To be treated with dignity
- Confidentiality
- A complaints or disputes resolution system which is fair, accessible and effective
- A non-judgemental attitude
- Clear guidelines for the use of their services
- Good record keeping so that you do not have to continually re-present your case

What if you live in an isolated area?

If you live in one of the capital cities or in a major regional centre, many of these support services will be easy to find. For people outside these major centres, it is sometimes harder to get the support services you need around you. Privacy and confidentiality are also important issues in small communities.

Many HIV positive people in isolated areas use a mix of city-based and regional services. Some have a local GP that they use for day to day care but travel to a regional centre or capital city for three to six monthly monitoring visits with a GP or specialist who has more experience in treating people with HIV/AIDS. Some specialists do regular clinics in country centres, usually through sexual health services.

Some people with HIV use the free counselling services provided by their nearest sexual health centre. Others have found counsellors in community health centres who can provide them with support. The AIDS Council in your capital city or a regional branch of the council should be able to help you find skilled and confidential support services.

It is worth doing some research to find out what is available in your area. In New South Wales, the local Area Health Service of the Health Department has an AIDS co-ordinator who can help you find your way around local services. In other states and territories, the AIDS/Communicable Diseases Section of the Health Department or the AIDS council should be able to help.



MONITORING YOUR HEALTH

HIV/AIDS

can be fairly unpredictable. You may feel well but it is hard to tell from that just what the virus is up to. Having regular health check-ups can give you an early warning about changes in your health and give you more time to decide what to do about them.

being aware
informed choice
time to decide

Regular monitoring allows you to track any changes in the concentration of HIV in your system, the effect of HIV on your immune system, and the emergence of any associated infections or symptoms.

Being aware of these changes in your health puts you in the best position to deal with them, either by going onto treatments, changing the treatments you are on, making adjustments to your lifestyle, getting additional support and so on.

Most people with HIV/AIDS who are not experiencing bouts of illness are monitored by General Practitioners (GPs) with some experience in treating people with HIV. Monitoring is not just about tests and results. Over a period of time, you and your GP can get a clear sense about how your body is dealing with HIV and will be in a better position to detect early changes in your health and to make plans to deal with these changes.

It's important that the person who is assisting you in your monitoring (usually a GP) knows about how HIV/AIDS will affect you in particular.

If you are a woman with HIV/AIDS, try to find a GP who has experience in monitoring women with HIV/AIDS or who is connected to a specialist with this experience.

It might be useful for you to keep a health diary or notebook in which you record test results, treatments, symptoms, reactions to medications and other things associated with your HIV monitoring. This can be a valuable tool for tracking changes in your health over time.

Some of the tests which can help you see how your health is going are described below.

Viral Load

This test measures the amount of HIV circulating in your blood and is used to show how active the virus is at any particular time. It is also used to measure how effectively the treatments you are on are working.

The results are given in ‘copies’ — a measure of the amount of virus present in one millilitre of blood. A low result means low concentration of virus. People generally get concerned when their viral load goes over 100,000 copies but it’s important to look at your pattern of viral load tests over a period of time to get a better idea of how much virus you have. Viral load is very individual, and the levels of viral load that might be cause for concern will be different for different people in different situations and also may vary according to when the test was taken. Having regular testing will help give you a better overall picture. Never place too much emphasis on a single test result, as they can vary. Talk to your doctor about what your particular results means to you.

HIV antiviral drugs aim to reduce viral load to ‘undetectable levels’. ‘Undetectable’ doesn’t mean that the virus has gone completely, just that the test isn’t sensitive enough to pick up really low concentrations. If your virus is undetectable over a period, it means it is replicating (or making copies of itself) at negligible levels. So far, no treatment or combination of drugs has been shown to eliminate HIV altogether, although many do allow people to maintain extremely low levels for



long periods of time. Viral load tests are done on blood, so they don't measure concentrations of virus in other parts of the body like lymph glands and other organs. You cannot tell how much HIV is in your semen or vaginal fluid from a viral load test taken from your blood. You should not assume that your blood viral load necessarily indicates you are more or less likely to transmit HIV or AIDS: this depends on a whole lot of factors.

When should you think about viral load testing?

- After an initial diagnosis of HIV
- Before you start or change treatments
- A month after starting or changing treatments
- When you are experiencing a change in your health (new symptoms or infections)
- Prior to conceiving, during pregnancy, just before and just after birth
- Every three to six months if you are well

CD4 Counts

The CD4 (or T-cell) test is a measure of how your immune system is coping. People with a healthy immune system usually have a CD4 count of somewhere between 500 and 1200. It's generally considered that a CD4 count of below 300 shows that some damage to the immune system is occurring. CD counts of 200 and under suggest quite a bit of immune damage has been done, and that you could be at risk of developing HIV-related infections or illnesses. CD4 counts can change quite significantly during the day and from one day to another. They are also affected by things like the presence of other short-term viral illnesses or infections in your body.

CD4 counts can also go up and down while you are on treatments. It is important to look at your CD4 count together with your viral load and to track both of these over time to get a better idea of what is happening. A single result is very difficult to interpret, but over time, you might begin to see a pattern or trend upwards or downwards.

You can monitor your CD4 count every three to four months if you are well and more regularly if it starts to drop below 300 or changes very suddenly.

As more is learned about HIV, ideas about the best way to treat it get changed and modified. Since HIV drugs can cause side effects in the short or long term, you need to weigh up the question of when to start against the risk of any treatment. Most people would be advised to think about HIV treatment if their CD4 cell count was at or below 250. Some people choose to start sooner, particularly if they have been diagnosed right at the time at which they were infected. Sometimes, people with stable CD4 counts above 250 will opt not to take treatment until they really need to. This is something important to talk about with your doctor.

Monitoring for Women

In addition to the above, women are encouraged to have a gynaecological screen every six months including a pap smear. HIV/AIDS can also make you more susceptible to a number of other conditions including thrush (vaginal candidiasis), genital warts, pelvic inflammatory disease, menstrual irregularities, and premature menopause. There may be interactions between oral contraceptives and some HIV treatments. The other time you may want to monitor your viral load and CD4 count carefully is during pregnancy. It's important to have a low viral load and good CD4 count during pregnancy, since this reduces any risk to both you and to your baby.

Monitoring for Men

Having HIV can affect the way the body deals with other infections such as sexually transmissible diseases. Sexually active men with HIV should have regular checks for sexually transmissible infections. Gay men should also have regular examinations for anal warts. Some STIs make it easier to pass HIV on to others. Regular checks should be a part of safe sexual practices.



Other monitoring

Hepatitis affects the liver so any hepatitis may affect the way your body processes HIV treatments. If you have hepatitis you may not be able to tolerate some of these drugs. You can be vaccinated against both hepatitis A and B.

HIV can affect all parts of your body. It is important that you have a regular (three monthly) general check-up to see if you have any other symptoms or minor infections that might be placing a strain on your immune system. It's best if you can find a GP who can do this on a regular basis so that you build up a picture of your general health over time and compare your health at each visit with the visit before.

It is also important to monitor other areas of your health, like your dental health. Infections and other problems in your mouth can indicate HIV viral activity and can lead to a general deterioration in your health if they are not treated early. Try to find a dentist who knows about treating people with HIV/AIDS. Your GP or AIDS council will have a list.

It is impossible to summarise here all of the tests and monitoring you might experience over time. There are a few publications listed in the resources section which can help find out about other tests and monitoring.

It's Your Choice

Remember, it's up to you to decide what monitoring and treatment you have. Regular monitoring puts you in the best position to make informed choices about treatments.

There is still quite a bit of debate about the best time to start HIV treatments. Monitoring helps you build up a picture of your experience of HIV/AIDS and allows you the freedom to make choices about what to do next.

WORKING WITH YOUR GENERAL PRACTITIONER (GP)

Your relationship with your GP

It's important to get this relationship right. A good relationship with your GP can maximise your health and your ability to maintain your independence.



positive relationship
active role
clear understanding

It's up to you to some extent to define what sort of relationship you want. Some people with HIV/AIDS rely on their GP for expert advice and follow their advice to the letter. Others think of their relationship with their GP in terms of a partnership, preferring shared decision-making, with the GP bringing information to the relationship to assist the person with HIV in decisions about treatment and care.

GPs have different styles. Some prefer a relationship with their patients in which they give advice, whilst others prefer a collaborative relationship in which the patient takes an active role in decision-making. Some GPs treat you as a whole person, taking an interest in all aspects of your life. Others take a disease-specific approach, concentrating mostly on you in relation to your HIV disease.

You should shop around until you find a GP with the combination of skills and style that suits you. If you are living in rural or remote



areas it may be harder to shop around as there may be few GPs with HIV/AIDS experience or interest. It's OK to talk with your GP about how you would like your relationship with them to work and to expect that they will try to fulfil your needs.

Having one GP who monitors you over a long period of time can improve your quality of care because the GP gets to know about you and your particular path through HIV/AIDS. The GP builds up a good history of your illnesses and the treatments you have been on. Moving regularly between GPs can break this consistency of care and means that it's harder for each new GP to get a clear understanding of what you need.

Choosing a GP

It's a good idea to think about what you want from your relationship with your GP. You may be relying on them for care and support for a number of years. **You are the customer and you are purchasing a service from them, usually through your Medicare card.** You do have some purchasing power and it's OK to shop around until you find what you want.

Don't be afraid to 'interview' your GP to find out how they work and what they think about caring for people with HIV. If they seem reluctant to have a discussion with you about how they work this might give you some indication about how other discussions you may want to have with them will go. Don't forget that there are a lot of trained and dedicated GPs out there. Don't be afraid to make a choice that suits your needs.

If you are in an isolated area or in a place where there aren't many other people with HIV your choices might be more limited. Your state or territory AIDS council or PLWHA group might be able to help with some names.

Agencies are a bit reluctant sometimes about recommending GPs. They'll give you a list but will not usually provide recommendations. Talk to other people with HIV/AIDS if you can. They might be able to tell you about their GPs. Don't necessarily write a GP off if one person says that they have had a bad experience with them. It might still be worth checking them out.

Questions you might ask as part of your selection of a GP:

- How do you like to work with your patients?
- Have you had other people with HIV as patients?
- (For women with HIV/AIDS) Have you treated other women with HIV/AIDS?
- (For people who use recreational and/or injectable drugs) How do you work with people who use drugs?
- How do you keep up with the changes in treatments?
- Are you able to prescribe antiviral therapies? (Not all GPs will have done the necessary training to allow them to legally prescribe HIV antiviral treatments.)
- If not, how do I access these therapies if I use your service?
- What do you think of complementary therapies?
- What arrangements do you have in place to protect my privacy?
- (For people in rural and remote areas)
What happens if I need to see you in a hurry?
- What happens if you are not available?
- Do you make house calls if I am unable to get out of bed?



- What happens after hours or when you go on leave — do you have a locum or after-hours service?
- (For parents) Can I bring my children along when I come to see you?
- Do you bulk bill? (That is can I just use my Medicare card or do I have to pay up front and claim back from Medicare? Is there a gap between what you charge and the Medicare rebate I will get back?)

It might be worth writing your list of questions down and even jotting down the answers you get back so that you can reflect on them later to help you make up your mind.

If all this seems too hard, there's a simple way to choose a GP. Do you like them? Do you enjoy being with them, find them human, like their sense of humour, their hair colour? That, coupled with a bit of an interest in HIV/AIDS on their part might be the perfect combination you need!

Working with your GP

Some people get nervous when they go into a doctor's surgery. That is not surprising. They can be quite frightening places. Even if you have planned what you want to say or ask, you can forget really easily when you are in there and end up just sitting there nodding. It's sometimes helpful to sit and think about what you want to know or discuss before you go in. Write down the things you are concerned about, the symptoms you have been having, the questions you want to ask. Take this list in with you and refer to it when you are with the GP.

Don't be afraid to ask questions or to ask the GP to set out all the options for you so that you can make a choice. Use words like 'choice' so that they can see that you want to be in charge of making the decisions.

Treat the time you have with your GP as ‘your time’ and let them know if you don’t like the service you are getting. For instance, if the GP takes three telephone calls while you are trying to decide on whether to change treatments, let them know that you would like their attention and that you find the interruptions distracting.

This is all sometimes hard as you may not want to cause a problem, but remember, you are the customer and they are selling a service. You have the right to comment on the quality of what you are purchasing.

How does the GP contribute to your care?

The GP is often a central point of reference for your care and monitoring. They can: regularly monitor your HIV viral load, CD4 count and other indicators; prescribe drugs to stop you getting opportunistic infections; prescribe, monitor and change antiviral regimes; look after your general health; carry out regular sexual and reproductive health checks; pick up early changes in your health; make referrals to specialists if necessary and communicate with HIV/AIDS specialists to ensure that you are able to take advantage of any developments in HIV/AIDS treatments.

They also have a role in providing you with support and in referring you to other services like community nurses, counsellors, dietitians, dentists, physiotherapists, specialists like physicians, surgeons and obstetricians.

GPs also have a role in referring you to hospital for investigation and treatment if necessary and in providing your follow-up care after hospitalisation. If you are being hospitalised, the GP will usually give you a letter which summarises your history of HIV illness, current



treatments, allergies and so on. The hospital will also generally give you a letter to take to your GP after hospitalisation, setting out what has happened to you in hospital and informing them of any changes in your treatments.

GPs can also provide home-based care for you if you are too sick to leave home. They can manage your pain relief and symptom control as well as contributing to the co-ordination of your care at home.

Principles of best practice

- Up to date knowledge of HIV treatment options
- Systems for protection of patient privacy
- Bulk billing for long-term patients
- Relationship with HIV specialists/HIV treatment hospital
- Participation in on-going HIV education/training
- Non-judgemental attitude
- Arrangements for consistent care — locum, after hours
- Recognition of social and emotional issues and their impact on health

*principles of
best practice*

the treatments maze

THE TREATMENTS MAZE

Keeping yourself informed about HIV treatments can be a full-time job. It can also be frustrating and confusing.



People around you seem to talk in a language which is made up of the letters and numbers for a whole lot of drugs which can be hard to keep track of.

 PAGE
27

This section sets out some of the basics of the HIV treatments available through the medical system and points to places where you can get more information.

Treating what?

There are three basic types of treatments available:

- treatments used against the HIV virus itself (antivirals);
- treatments used to stop you getting opportunistic infections (prophylaxis) or to treat them if you get them;
- treatments to relieve or eliminate symptoms associated with HIV disease and the side effects of other treatments.

We will look at these one by one.



Treatments used against HIV itself (antiviral treatments)

From the time you are exposed to HIV, the virus makes copies of itself (replicates) in the body. Antiviral treatments aim to reduce the amount of HIV in the body to the lowest level possible and to keep your HIV disease at a manageable level, by preventing HIV from replicating. Experimental anti-HIV drugs also attempt to stop the virus from entering and infecting cells, but these are not commercially available yet.

AZT was the first antiviral treatment used for HIV. Used on its own, it seemed to have a positive but temporary effect. Since the early days of single (or mono) therapy, a number of different drugs have been developed. Used in combination with each other, these treatments have significantly reduced the impact of HIV on people and dramatically reduced death rates.

Side effects

The available treatments for HIV are far from perfect. They can have a range of short and long-term side effects, and it is also possible for HIV to develop resistance to one or whole classes of these drugs.

The question of side effects is significant. Many of the common side effects from treatment (diarrhoea, nausea) can be managed or treated to help you better tolerate the drugs. Often they decrease or disappear altogether given time.

Other side effects can develop over time, and may be more significant in terms of your health and wellbeing. Stories of drug side effects like body shape changes and metabolic complications are understandably alarming. However, the advantages of treatment, especially if you have a low CD4 count, may far outstrip any risk. You should discuss the risks and benefits of any new treatment with your doctor. Some side effects can be managed fairly easily; others may be more difficult. There are resources available which discuss side effect management in detail.

Deciding whether or when to treat

This is a difficult decision for people with HIV, particularly if they are reasonably well. It's rarely an emergency. It's usually OK to take some time find out about the pros and cons of taking treatments and to talk to people who can help provide you with information and answer your questions.

It's not as simple as popping the occasional pill. There are many tablets to be taken each day, some with food, some without. For the pills to work, you have to take them exactly in the way they are prescribed without missing any doses. If you skip doses, the level of drugs in your body drops and the virus gets a chance to adapt to the drugs, eventually making them useless. Not missing doses is the most important contributor to how well the treatments work.

Some things to consider talking to your doctor about

- How much virus have I got at the moment? (Viral load)
- How much damage has it done to my immune system (CD4 count)
- What are my chances of keeping up the treatments on a regular basis?
- What other options are there?

Don't be afraid to get a second opinion about these things. This is a big decision. You could talk to the treatments officer at your local AIDS council, someone at your local PLWHA organisation or another doctor with HIV experience.

You and your GP or treatments officer could do a 'lifestyle audit' which might help you discuss the effect of combination therapies on your life and the likelihood of you being able to effectively take the combination of drugs prescribed over the longer term. For instance, if you travel a lot, it might be helpful to choose a combination of drugs which don't require refrigeration. If you are a shift worker, you might need extra assistance to get into a set pattern of taking the drugs. Remember, quality of life is important too.

Many centres have access to health care workers who will work with you specifically on these issues. Taking the time to see them, even once, may help you to predict any potential problems before they arise.



About the drugs

This is the part when everyone seems to break into another language and you can get really confused. There are lots of ways to find out more information — your local AIDS council or PLWHA group is a good start.

These drugs are broken up into classes, depending on the way that they work against the virus.

This table shows some of the drugs in the four classes. Each drug has at least two names. Names are shown as common name (drug name, company trademark name). Most people talk about the drugs using the common name.

Nucleoside Reverse Transcriptase Inhibitors

AZT (zidovudine, Retrovir)

ddI (didanosine, Videx)

ddC (zalcitabine, Hivid)

3TC (lamivudine, Epivir)

d4t (stavudine, Zerit)

abacavir (Ziagen)

Combivir (AZT and 3TC in one tablet)

Trizivir (AZT, abacavir and 3TC in one tablet)

Non-nucleoside Reverse Transcriptase Inhibitors

nevirapine (Viramune)

delavirdine (Rescriptor)

efavirenz (Stocrin)

Protease Inhibitors

saquinavir (Invirase and Fortovase)

ritonavir (Norvir)

indinavir (Crixivan)

nelfinavir (Viracept)

amprenavir (Agenerase)

lopinavir/ritonavir combination (Kaletra)

Nucleotide Reverse Transcriptase Inhibitors

tenofovir (Viread)

The principle of combining treatments

Unfortunately, you can't just pick a combination and dive in. Some work better together than others, some combinations don't work or can't be taken together at all. Some of the drugs have lots of side effects, some have very few. In addition, people tend to respond to the drugs quite differently. So if your friend gets side effects from one combination or drug, this doesn't necessarily mean you will experience the drug in the same way. Some might fit better into your lifestyle (for example, you take them less often or they are easy to carry around with you). Others are a bit harder to adjust to.

It is standard practice to have people on a combination of at least three drugs, usually from at least two of the available classes. Sometimes people are offered just two drugs in combination but this is usually when other drugs do not work for them or they have experienced severe side effects. The most common 'standard combination' includes two nucleoside reverse transcriptase inhibitors in combination with either a non-nucleoside reverse transcriptase inhibitor or a protease inhibitor.

If you are on only one or two of these drugs it's important that you ask your doctor to explain why that is. Remember, HIV treatment is a rapidly changing area. It's OK to ask questions and to be reassured that you are on the most effective treatments possible — it's your life we are talking about here!

What drugs shall I take?

This is a difficult area to cover briefly, and there is no "right or wrong" answer. There are some important things to consider:

- What stage of disease are you at (viral load, CD4 count, symptoms)? (If you have a very high viral load, you may need to start with a drug which has a stronger antiviral effect).
- What prior treatment have you had? (You may be resistant to some drugs, or not be able to tolerate their side effects).



- What treatments are you on now? (You might want to change, due to side effects or a rising viral load suggesting the drugs aren't working as well. You might be considering pregnancy).
- How easy will it be to take the particular combination? (Some drugs are now available in once-daily dosing, with or without food).
- What side effects are there? Can they be managed easily?

Taking the drugs

Try not to pick a combination that you will have problems keeping to. If you pick a combination that you can't really maintain, you give the virus a head start in developing resistance.

Things to consider

- Your track record with taking drugs — have you had trouble completing a course of antibiotics?
- Your lifestyle — does your job make it hard to remember to take medication in the middle of the day? Do you keep irregular hours and eat at different times every day?
- Storage of the drug and other matters — Would you have trouble taking a drug that needed to be refrigerated? Do you have children in the house who could raid the refrigerator? Do you travel a lot?

The importance of taking the drugs as prescribed

Taking the right dose at the right time is really important. Skipping doses can mean that the drug becomes ineffective against the virus. Taking a drug on a full stomach when it's meant to be taken before eating can make the drug ineffective. Make sure you know what each drug needs to make it effective.

There are plenty of ways to help you remember to take your drugs on time. You could experiment with some of these until you find the least intrusive, most effective way to remember to take your pills:

- portable pill boxes with a timer that you can set to beep each time you need to take a drug — available from your local AIDS council or doctor;
- dosette box — this is a box which lets you set out your pills for the week in labelled sections so you can easily see what you have taken and what you need to take next (available from chemists or AIDS councils);
- a calendar or diary in a prominent place at home and work which you can tick off each time you take your pills;
- establish a routine which associates pill taking with meals;
- get an electronic diary and program it to remind you when to take your pills;
- keep a supply of your pills in key locations (home, work, knapsack/briefcase, boyfriend/girlfriend's house);
- prepare for holidays by getting a stock of drugs in advance;
- keep an eye on the 'use by' dates, use up the closer dates first so you don't suddenly run out of stock;
- find out from other people with HIV what they do to remember their pills;
- get support from partners, friends, family or health care workers to help you take your pills without missing doses.

Try to pick strategies that won't burden you too much. You want just enough to remind you to take your pills but not so much that you have HIV in your consciousness all day every day. Remember also to take care not to leave the reminders lying around if you have not told people at work or others about your HIV status and don't want them to know.

Changing combinations

Combinations fail or stop working for all sorts of reasons. You need to have regular monitoring whilst you are on combination therapy so that you can find out as early as possible if the combination you are taking has stopped working or is not being as effective as it was originally. You also need to be monitored after each change in combination to see if the new combination works. During these times, you may need more frequent viral load tests.



Treatments for opportunistic infections

HIV affects your immune system — the part of your body which normally fights off infections. Most healthy humans carry around a set of bugs which are kept at bay by their immune system — that is, they have been exposed to a whole series of potential infections but don't get sick because their healthy immune system fights to stop these infections getting established in the body.

HIV damages parts of the immune system. Once the damage reaches a certain level (roughly indicated by your CD4 count), some of the infections your body could normally deal with get the chance to establish themselves and make you sick. These are called Opportunistic Infections (OIs) — they take the opportunity to set up when your immune system is not working properly.

One of the absolute facts about HIV antiviral treatment is that these drugs have prevented a great many people from developing opportunistic infections associated with HIV/AIDS. Many of the infections once seen fairly commonly in people with low CD4 counts are now quite rare. However, some people do still have immune damage, and may be at risk of some of the infections described below. It's generally considered that a CD4 count of 200 or less is when you start to be at risk of these infections.

There are a number of drugs that you can take to prevent you getting these opportunistic infections. This is called opportunistic infection prophylaxis (or prevention). The dose for these treatments is usually less than the dose you would need for treating the infections.

The decision to start these treatments is usually based on the level of your CD4 count — the marker of your immune system function. When you get down to, or below, a certain level of CD4 cells (set out in the table below), it's time to have a discussion with your doctor or treatments adviser about OI prophylaxis.

There are parts of your immune system that don't get damaged and they continue to fight common cold and other infections.

Many opportunistic infections are treatable but obviously its better to avoid them if you can!

Here is a brief summary of some of the common opportunistic infections, their prophylaxis and treatment.

Name:	Pneumocystis carinii pneumonia
What is it?	An infection of the lungs
How to avoid it?	Take an antibiotic (Bactrim or Septrin). Some people are sensitive to Bactrim. Talk to your doctor about an alternative if this is the case.
When to think about prophylaxis?	When your CD4 count drops below 200
How is it treated if I get it?	With Bactrim or Septrin or a drug called pentamidine

Name:	Mycobacterium Avium Complex (MAC)
What is it?	An infection which can set up in your key organs — spleen, lymph nodes, bone marrow, gut or lungs
How to avoid it?	Take rifabutin or azithromycin
When should I think about prophylaxis?	When your CD4 count is less than 50
How is it treated if I get it?	It is treated with a combination of drugs.



Name:	Toxoplasmosis (Toxo)
What is it?	An infection which causes an inflammation of the brain. It can also effect other organs (gut, eyes, heart, lungs).
How to avoid it?	Take Bactrim or Septrin. A blood test will tell you if you have been exposed in the past and if you are at risk in the future. Those that have not been can also prevent it by avoiding raw or undercooked meat. Avoid cleaning out your cat's litter tray
When should I think about prophylaxis?	When your CD4 count drops below 100
How is it treated if I get it?	There are a number of treatments for toxoplasmosis.
Name:	Cryptosporidiosis (Crypto)
What is it?	Small protozoans which cause diarrhoea
How to avoid it?	There is no specific prophylaxis but it is found in some cities' drinking water – boil or filter it if you are in one of those cities.
How is it treated if I get it?	It's hard to treat but there are some reasonably effective antibiotics.
Name:	Cytomegalovirus (CMV)
What is it?	A herpes virus that can cause serious problems in the gut, throat, spine, eyes or brain. A blood test will tell you if you have been exposed in the past and if you are at risk in the future.
How to avoid it?	There is no specific prophylaxis.
How is it treated if I get it?	CMV can be suppressed by a number of drugs.

Name:	Candidiasis (Thrush)
What is it?	A fungal infection, usually in the mouth and throat or in the vagina
How to avoid it?	Thrush can be made worse by anything that exacerbates the amount of warmth or moisture in your vagina (eg. wearing tight or nylon pants).
How is it treated if I get it?	Thrush responds to a number of anti-fungal treatments.

Name:	Kaposi's Sarcoma (KS)
What is it?	KS is a cancerous malignancy caused by a herpes virus. It can result in lesions appearing on the surface of the skin or inside your body. These lesions are purplish in colour and are slightly raised on the surface of the skin.
How to avoid it?	It is thought that the KS virus is spread through oral/anal contact so rimming is a risk activity for this virus.
How is it treated if I get it?	There are a number of treatments for KS, including radiotherapy and chemotherapy.



Other treatments

HIV can affect all parts of the body. Each person with HIV has a different set of associated illnesses, infections or symptoms. You may be prescribed a range of drugs to treat these different illnesses, infections and symptoms and you will need to incorporate these into your treatment regime.

You may be on a range of other treatments – methadone, oral contraceptives, treatments for non-HIV related illnesses, or drugs for side effects (eg. lipid-lowering drugs, or anti-diarrhoea treatments). You will need to find out from your GP or specialist whether these interact with the combination therapies you are on.

COMPLEMENTARY THERAPIES

Many people with HIV/AIDS have used complementary therapies and practices to assist them in dealing with HIV/AIDS.



decisions and choice
shopping around
choosing your therapist

Complementary (or alternative) therapies are those therapies and practices which are not generally associated with Western medicine or provided through the Western medical system.

PAGE
39

This chapter summarises the information presented in the PLWHA ACT Complementary Therapies Handbook and in the AFAO booklet Complementary and Alternative Therapies — a Guide for People with HIV/AIDS.

Why do people use complementary therapies?

For many years, people have supplemented the care they receive from doctors and the medical system with care and support from other practitioners who provide alternative or complementary therapies.

These therapies cover a very wide range of approaches and practices. Some, like massage, float-tanking, use of guided visualisation audio tapes and hypnotherapy, are aimed at increasing relaxation and diminishing stress.



Others take a more intrusive approach and are aimed at treating problems or symptoms. These include such therapies as acupuncture, Bach flower remedies, homeopathy, herbalism, naturopathy and so on.

The PLWHA ACT handbook provides a useful summary of these and other therapies and explains how they are used by people with HIV/AIDS.

Just like in Western medicine, there are currently no complementary therapies that can cure HIV illness.

Choosing therapies

The range of available therapies is enormous and within each discipline, each therapist has his or her own particular style or approach.

If you are shopping around for complementary therapies you might want to think about some of these things:

- What am I trying to fix or achieve?
- Who is practising complementary therapies in my area?
- What are other people with HIV/AIDS using?
- Are they happy with the results?
- What evidence exists for the therapy?
- How effective is it?
- How much will it cost me?
- Can I get it more cheaply somewhere else?

Finding out about complementary therapies

There are plenty of ways to research complementary therapies. You can ask your local AIDS Council or PLWHA organisation about therapies and look at the publications they have which explain therapies. You can surf the net and check out what each therapy does, or says it does. You

can talk to other people with HIV/AIDS in peer support groups or through PLWHA organisations to see what they are using. You can go to your local library and see what they have on different therapies. You can look at some of the complementary therapy magazines available at newsagents. You can check your local paper to see who is advertising.

Choosing your therapists

Decisions about who to use as a therapist are similar to the decision you make about selecting a GP or other health provider. It's obviously better to find someone who you can feel comfortable with and trust.

Again, don't be afraid to shop around and to interview prospective therapists. You could ask:

- How do you work?
- Have you worked with other people with HIV/AIDS?
- What therapies do you use?
- What qualifications do you have to administer these therapies?
- Do you belong to a professional or industry group or association?
- What evidence do you have for their effectiveness?
- How long will the therapies take?
- How much will it cost?
- How will you protect my privacy?

There are plenty of therapists out there. If you are feeling pressured or you don't like the approach your prospective therapist is taking, have a look around for another one. One good rule of thumb to use might be to see how the therapist seems to reflect the therapies they promote: do they look healthy, happy, stress free? You might also want to use this in choosing your other care providers!

It is important to know what training your potential therapist has had and whether they have treated people with HIV/AIDS before.



How to work with your complementary therapist

In the same way as you are able to take control over the decision made about your medical care, you can have a relationship with your complementary therapist which is based on them presenting you with options and you making decisions about what to use.

You can take your time to decide what therapies to use and ask for some written materials to take away and read to help you to make a decision.

You can negotiate the therapy in stages so that there are clear times when you can reflect on how the therapy is going and decide whether to proceed with the next stage or not. This also means that you are in control of the cost as you are buying the therapy in stages. This also gives you an opportunity to evaluate your progress under the therapy.

It's important to discuss your medical treatments with your complementary therapists so that they know what you are taking and can let you know about any interactions between therapies. For the same reason, it is also important to discuss your complementary therapies with your GP or specialist.

If you are not happy with the service you are receiving from your complementary therapist you could:

- discuss your concerns with them;
- stop going to them;
- find another practitioner and seek a second opinion;
- talk to your local AIDS council or PLWHA group;
- talk to a consumer group like Consumers' Health Forum of Australia or the Australian Consumers' Association;
- find out if their work is covered by a professional body and talk to them about your concerns.

NEUROLOGICAL AND PSYCHOLOGICAL COMPLICATIONS OF HIV

This chapter discusses some of the neurological (brain and nervous system) complications which can affect people with HIV.

mental wellbeing
health monitoring
treatments

It also considers some of the psychological and psychosocial effects of HIV infection, including depression.

Being HIV positive can obviously affect your state of mind or mental wellbeing. In addition, sometimes HIV itself, or HIV-related infections, can affect your brain and central nervous system, leading to changes in thinking, behaviour, emotions or physical co-ordination. The good news is that with current HIV antiviral treatments, many of the infections which can cause neurological symptoms in advanced HIV disease are now quite rare. However, if you have AIDS or a low CD4 count (especially less than 200) you may be at greater risk of some of these problems.

The chapter is divided into three parts.

The first looks at how HIV and some infections related to it can affect your brain and nervous system.

The second looks at how HIV infection may affect your mental health more generally, and may lead to some quite common problems for many HIV positive people, like depression, ongoing sadness, or anxiety – and what you can do about this.

The third section briefly discusses how some HIV antiviral treatments may affect your mood, behaviour or nervous system.



How can HIV affect your brain and central nervous system?

HIV can affect many parts of your body.

It can affect your brain in several ways.

- The virus itself may have a direct effect, as in HIV-related dementia. The good news: HIV treatments can improve your CD4 count, and this is probably the most important factor in preventing dementia and other HIV complications. There are also some HIV treatments which might be particularly useful in controlling HIV levels in your brain and spinal fluid, helping prevent neurological problems.
- You may develop an infection — as a direct result of having HIV — which can affect the way you think, feel, and move. Many of these infections are treatable and preventable. The biggest risk factor is having a very low CD4 count. One example of this is the infection called toxoplasmosis (see Opportunistic Infections).

Because of HIV antiviral treatment, the occurrence of many of the neurological illnesses which affect people with very low CD4 cell counts or with AIDS has dramatically decreased. Many of these infections and conditions are now relatively rare. In addition, some — like toxoplasmosis — can be prevented if you are at risk, by using prophylactic treatment, and by avoiding any possible exposure to the bug. If you have a CD4 count of under 200, talk to your doctor about how to avoid coming into contact with the bugs that might cause infections. Some basic preventative measures incorporated into your daily routine can really reduce your risks of encountering these bugs. Many people have been exposed to toxoplasmosis already at some point in their life. If you know you are positive to this bug, talk to your doctor about how to keep it controlled.

Still, it's useful to be aware of any symptoms you might have which could suggest that you do have an infection or illness which is affecting your brain. If the symptoms come on very rapidly, or are severe, you should get immediate help from a doctor or hospital. If your doctor

thinks you do have an opportunistic infection affecting your brain or nervous system, they will advise you if you need to go to hospital, or arrange for you to see a specialist.

Signs that you might have a neurological complication arising from HIV which needs urgent medical attention may include:

- severe, sudden headache;
- vision disturbances — blurred or double vision, painful sensitivity to light;
- problems walking or balancing;
- slurred speech, confusion, “the words are coming out wrong”;
- a very high fever;
- hallucinations;
- numbness, weakness or tingling.

It can be scary to have these symptoms. If you can, take a friend to a doctor with you so they can ask questions and hear what the doctor has to say, particularly if you are feeling confused. Signs like the ones described above, especially if they are acute and “come out of nowhere” might mean you need to go straight to hospital. Your doctor can also refer you to a neurologist or other specialist for assessment or treatment.

HIV-related dementia

Most people with HIV and AIDS will not develop HIV-related dementia, but some people continue to develop this condition, even in the age of improved treatment. As part of your health monitoring — particularly if you have AIDS or a low CD4 count — you might at some time need a referral to a specialist neurologist, who can assess your risk of developing dementia. One of the tests they might do is to take some fluid from your spine (a lumbar puncture) to see how much HIV is present in your brain and spinal fluid. (Sometimes, you can have higher amounts of virus in this part of your body than in your blood). This may help work out if you are at risk of dementia. If you do have higher levels of HIV in your spinal fluid and brain, you may want to change your HIV antiviral treatment, since some drugs “get into the brain” more effectively than others, and can help reduce risk of dementia.



Dementia is understandably a terrifying prospect. Knowing what early signs or symptoms are, and ensuring that you have support around you if you do think you have signs of dementia, are crucial.

Dementia in its very early stages may have quite mild symptoms. You shouldn't panic, or over-read fairly common occurrences as indicating you have dementia. Forgetting where you put your keys or the name of your new boyfriend's uncle are unlikely to be signs of dementia. Depression and anxiety are among the much more common causes of this sort of forgetfulness. But if you begin to notice a pattern of forgetfulness developing (you forget where you put things more often; you start to forget names, appointments and other details quite regularly) you may need to have this investigated. One of the characteristics of dementia is that the person themselves may be less aware of the symptoms and signs than are the people around them.

Other symptoms of dementia can include:

- confusion and lack of concentration;
- fogginess or cloudiness in thinking;
- problems with movement and co-ordination; loss of limb strength;
- behaviour changes e.g. reversion to 'childishness'.

If your doctor thinks you might have dementia, you will be referred on for a special assessment and tests, including tests of your mental and physical responses. Take a friend or family member along if you're worried.

Having support around you — a trusted friend, partner or family member — will be one of the most important things. There are services available that you might be referred to. In some states, these will have experience with HIV-related dementia and its care. Your AIDS council will be a good source of information about services for dementia. They will also be able to explain the legal issues that can arise with dementia, such as guardianship and power of attorney.

Depression and related conditions

There's a lot of talk about depression and HIV. It can be very confusing trying to work out the medical jargon from your reality: whether you

are clinically depressed, or simply having a low mood, and how to get the right kind of support.

People sometimes use the word “depression” to describe short-term unhappy feelings which might have a specific external cause (death of someone close, losing your job, relationship break-up, HIV diagnosis.) But this is often different from clinical depression, which can involve specific changes to your brain chemistry, and may cause particular “biological” symptoms (like sleeplessness and appetite changes) that last over a period of a few weeks or longer. Clinical depression might be caused by the same external “triggers” as a low mood, but there are usually other symptoms. Severe clinical depression should be taken seriously, because it can lead to suicidal thoughts. The important thing about clinical depression is that it responds in almost all cases to treatment with antidepressants.

There is also a related condition, called dysthymia, which manifests as a kind of chronic sadness, a bit like what is sometimes called “melancholy”, and which continues over long periods of time.

Feeling low

Feeling low if you have HIV is not uncommon. People with HIV report low moods and sadness due to a range of things:

- stress of diagnosis;
- uncertainty about treatment;
- not working;
- drug side effects;
- drug and alcohol use;
- changes in your body shape due to HIV or treatments;
- grief, loss;
- loneliness;
- loss of sex drive;
- poverty.

None of this is uncommon or surprising. Low moods shouldn’t be cause for undue alarm that there is “something wrong” with you.

You might find there are a range of options for dealing with these situations which do not necessarily involve taking drugs or seeing a psychiatrist. For example:



- peer support services at your local AIDS council or PLWHA group;
- talking to a doctor you trust;
- seeing a counsellor or social worker at your hospital, medical centre or AIDS council;
- generally looking after yourself: exercising, sleeping, eating well;
- cutting down on drugs or alcohol if this is an issue;
- going away with a friend for a weekend or a few days.

Clinical depressions

Sometimes however, people can develop more severe forms of depression, which may suggest you could benefit from medical treatment. Depression always reduces someone's quality of life and it can be life-threatening in more extreme cases. So-called "clinical depression" often has a set of recognisable signs and symptoms. Signs might be a combination of:

- extreme fatigue, lack of energy/motivation;
- crying frequently;
- poor sleep;
- inability to find pleasure in everyday things;
- inability to deal with day-to-day life — can't get up, can't go out;
- loss of appetite;
- suicidal thoughts.

People with severe depression have been shown to have a disturbance in the function of certain brain chemicals. This disturbance is able to be corrected by antidepressant drugs in more than 80 percent of cases.

If you experience some or all of these things, and if they are ongoing or get worse, you would almost certainly benefit from professional help. If this feeling is accompanied by other symptoms like panic, paranoia or delusions, you should talk to someone about this straight away. You can:

- tell a friend who you trust;
- see a GP;
- see a counsellor or treatments officer at your AIDS council;

- call an anonymous telephone crisis-line: some of these services offer advice, counselling and emergency support and are staffed 24 hours a day.

You may be referred on to a specialist, such as a psychiatrist or other mental health care professional.

Medication for depression: the choice is yours

Severe depression is treatable with a range of drugs. Sometimes, treatment is needed to prevent a person harming themselves or others. Drug treatments for depression work by ‘re-adjusting’ the upset brain chemistry that causes depression. But taking medication isn’t necessarily for everyone. For some people, antidepressants work well. Other people don’t want to take these drugs for a variety of reasons, both personal and medical. If you don’t wish to take antidepressants or other drug treatments — for whatever reason — make this clear and discuss alternatives with your doctor. This might include agreeing to regular counselling. You can’t be forced to take any kind of psychiatric medication — except under specific, extreme circumstances in which you are likely to harm yourself or others.

Herbal treatments for depression need to be used carefully if at all with HIV drugs. Talk to your doctor about any alternative treatment before you use it, to find out if it is safe and appropriate.

Can HIV drugs cause depression and other problems?

Most HIV drugs have some side effects. But some drugs can have neuropsychological effects, affecting your mood or nervous system. Efavirenz (Stocrin) is one drug which can have this effect — especially when you first start taking it. It can cause dizziness, wooziness, vivid dreams and sleep problems. Often, these stop after you’ve got used to the drug, but they may recur. Talk to your doctor if you are concerned or the symptoms continue.



Some research does suggest that other HIV drugs can alter your overall mood, and may even cause depression. Not everyone agrees about the evidence for this. Since depression in HIV is not uncommon, there's a sort of chicken-and-egg argument about treatments as a cause. If you develop depression after taking a new treatment, discuss this with your doctor.

Principles of best practice

- Living with HIV can raise many issues which can cause short and long-term 'blues' and depressed or low mood — these are quite common, and most often don't require medication.
- There are support services available for HIV positive people, including peer support and one-on-one counselling, through AIDS councils, hospitals, and community health centres.
- Confide in close friends if you think you may be seriously depressed.
- See a doctor if your depression is very extreme or worsens, or if you have delusions or suicidal thoughts.
- There are a range of medications to treat depression, but they sometimes have side effects. The risks and benefits of any medication should be explained to you. Talk to other positive people about their experiences.
- Don't be coerced into treatment. If you don't want to take antidepressant drugs, ask about alternatives, like long-term counselling.
- Anyone person you go and see about your mental health – doctor, nurse, counsellor, psychiatrist, AIDS council treatments officer – is bound by law to protect your confidentiality. They should treat you with respect and take your concerns seriously.
- Some HIV treatments can cause neuropsychological disturbances, like dizziness, wooziness, or sleep problems. Always talk to your doctor about the possible effects when you start or change treatments. If you can't tolerate the side effects, see if you can use a different drug or combination.

community care and support

COMMUNITY CARE AND SUPPORT

This chapter

sets out the range of home and community-based care services available and lets you know how to make best use of them. There may come a time when you need some help to maintain your independence at home.

services available
home-based care
how you qualify

You may be managing on your own or you may have a live in partner or carer. In either case, community services are available to help you to manage as your care needs change.

PAGE
51

You don't have to wait until you are in desperate need before you call on these services. Many of these services can lessen the burden on you and your carers by providing support and assistance even when you are relatively well.

There are a number of home-based care and support services which you can use.

Community nursing

Community nurses are usually attached to a community health service or to a specialist community nursing agency. They travel around communities taking care of people who are sick or debilitated at home.

They can provide a number of services such as:



- personal care — bathing, assisting with showering and personal hygiene;
- dressing wounds and monitoring healing;
- giving injections or treatments at home;
- providing emotional support;
- co-ordinating other care services;
- monitoring health and liaising with your GP;
- helping your carers by training them to give injections and to care for you in other ways.

You can usually get your GP or another health worker to refer you to your local community nursing service. A nurse will come out and do an assessment. This is a discussion to find out what you need and for them to explain what they can offer. Services are generally free, but there may be a small charge for some services.

Once you have been assessed, a nurse will visit your home to help with your care. The number of visits per week will depend on your needs and what you work out with the service when you are assessed.

These services understand that your needs will change over time. There might be some weeks when you need the nurse to visit every day or even more than once a day. There might be other times when a weekly visit is enough.

You will not always have the same nurse visiting your home, but most agencies will try to keep the number of nurses to a minimum so that you can develop a relationship with the nurse and so that he or she can get to know better what your needs are.

The agency that hires the nurses will have policies and procedures and the nurses they provide will be expected to abide by these. If you have any problems with the service you are getting, the agency should have a mechanism for you to ask questions or to make a complaint. You can ask the nurse who does your assessment what you should do if you are experiencing problems with the care you are getting.

Most agencies will also have an after hours ‘on-call’ system if you need assistance after normal working hours.

AIDS volunteer care agencies

AIDS councils and other agencies in the capital cities run home-based practical and emotional support services. These services train and support volunteers who provide a range of services for people with HIV/AIDS at home including:

- shopping;
- housework;
- personal care (bedside care, bathing etc);
- emotional support (talking, listening, spending time together);
- support for your carers.

These services are arranged differently in each city. For instance, in Melbourne, the Victorian AIDS Council uses ‘care teams’ to provide the services, whilst in Sydney the practical care is provided by Community Support Network, based at the AIDS Council of NSW, and emotional support volunteers are provided by Ankali Project, based at the Albion Street Centre. Your local AIDS council can tell you what is available in your area.

Most volunteer home-based care agencies can provide anything from a weekly visit to help with shopping or housekeeping through to constant care at home for people who are too ill to care for themselves.

What can you expect from a volunteer care agency?

- A professional approach to their service delivery;
- An assessment process which allows you to talk about your needs and allows them to explain how the service works;
- A clear set of policies and procedures made available to you as the client;



- Volunteers who are adequately trained, supported and supervised;
- A complaints or disputes resolution system which is fair, accessible and effective;
- Mechanisms for client feedback to the organisation;
- A non-judgemental acceptance of different lifestyles;
- Mechanisms to provide consistent care;
- Effective communication systems;
- Privacy and confidentiality;
- A philosophy with aims to maximise your independence and minimise the disruption to your home;
- A respect for the central role of your partner, family members and friends;
- Services which promote client self-determination and dignity.

Supervised care services

For some people with HIV/AIDS, care at home may not be possible. If you do not have a live in carer and you lose your mobility or your ability to care for yourself, you may need to spend some time in supervised care. People with HIV-related dementia – a complication which affects your ability to remember things and to function independently – sometimes require care in an environment where carers can provide around the clock support. Special dementia services exist in some of the capital cities. If these services are not available, care is generally provided in a hospital, hospice or nursing home.

Community transport

Some AIDS councils and local government councils run community transport services which can help you get to and from clinic and hospital appointments. Your clinic or AIDS council can help you find out about these services.

Meals on Wheels

Meals on Wheels services have come a long way in the last few years. Check them out. They can provide healthy meals on a regular basis and can take your particular health needs into account. They are usually associated with your local government council (the city you live in).

Domiciliary Care/Home Care

Some areas provide domiciliary (home) care services which include a clean linen service, equipment to help you manage safely at home and occupational therapists, nurses, physiotherapists and social workers to help you maintain your independence. Home care can assist with housework and some personal care.

Principles of best practice

- **Information available on what the service offers and how you qualify for services**
- **A non-judgemental approach by all staff and volunteers**
- **Privacy and confidentiality policies and procedures**
- **Trained and supported staff and volunteers**
- **Policies and practices which guide the way the service operates**
- **Access to a disputes or complaints system if you are not happy with the service provided**
- **Quality assurance measures to assist the service to maintain high quality care**
- **Client consultation about the way the services are delivered**
- **Reliability — services provided in a timely and efficient manner**

*principles of
best practice*



GOING TO HOSPITAL



In recent years,
the increased success of
HIV/AIDS treatments has
meant that people with
HIV/AIDS use hospital
services less and less.

56

Some people still require hospitalisation for the treatment of some opportunistic infections or for care associated with HIV-related dementia. People also sometimes need to be in hospital at times when the antiviral therapies they are on have stopped working or when damage to their immune system means that they experience a range of HIV-related infections and complications at the same time. You may also need to be admitted to hospital if you experience a reaction to the drugs you are taking or if you experience severe side effects.

A stay in hospital can provide an opportunity for a thorough re-evaluation of your treatment regime and for investigation of symptoms. It can also provide the people caring for you with some time out and a chance to recharge their batteries.

For shorter treatments and investigations, many hospitals offer day treatment services which mean that you do not have to stay overnight.

This chapter talks about how you can make use of the hospital system.

Day admissions

Some HIV/AIDS treatments are given into your vein and for these you will have to visit either the day stay unit of a hospital or a clinic which caters for this type of treatment. That is because these treatments need to be given slowly through the vein and you need to be observed for any complications that might arise. A treatment of this sort may take several hours.

You might need a course of treatments over a number of days, or treatment a few times a week over a number of weeks.

The length of treatment and time between treatments depends on the drugs being given and on what they are treating. It's good to know what to expect from a course of treatments, so find out as much as you can from your doctor before you start. You can ask questions like:

- What is it that you are treating?
- Is this course of treatment the only alternative?
- Why have you chosen this particular course?
- How many infusions (treatments) will I have?
- Over what period of time?
- How long will each one take?
- Are there any side effects?
- What is the success rate?
- What happens if I don't have the treatment?

It may be possible to plan the treatments around your work or other priorities. Don't be afraid to ask for what you need. Hospitals can be busy places and it may not always be possible to work around your schedule, but you have the right to expect some flexibility.



Being admitted to hospital

Different hospitals have different admission procedures. If you are a regular visitor to the hospital, you may be able to by-pass the emergency or casualty section and be admitted straight to the hospital ward. Some hospitals have streamlined their admission process for people with chronic illnesses like HIV/AIDS, diabetes, cancers and so on, who may only visit one hospital. This means that you can go straight to the familiar environment of the hospital ward and bypass the busy accident and emergency service.

On admission you will usually have to give a 'history' of your illness to a resident medical officer (RMO) or Registrar. RMOs are doctors at the first level of medical training after completing their university degree. They rotate from one speciality area to another as part of their post-university training and therefore will not usually have specialist HIV/AIDS knowledge.

Remember that you will usually not be feeling too good if you are admitted to hospital and your concentration and energy levels will probably be low. You can make the history-taking process easier and less draining on you if you keep a written record of your HIV/AIDS treatments and bring that with you to hospital. This will save the RMO having to ask a lot of questions and save you having to give the same answers to a new person each time you are admitted. It's a good idea to keep the record of your treatments in a special notebook so that it's easy to find when you need to go to hospital.

This record does not need to be very complicated but just needs to tell the story of the things that have happened to you medically since you were diagnosed with HIV. It might contain some of these things below.

History of your HIV infection:

- when you were diagnosed with HIV;
- when you think you became infected.

History of illnesses associated with HIV:

- episodes of infection or complications (pneumonia, KS, etc).

Current treatments:

- antiviral drugs;
- opportunistic infection prophylaxis (Bactrim etc.);
- other drugs (antidepressants, etc.);
- any complementary therapies you use.

Allergies, complications, unusual reactions:

- any drugs, investigations or treatments you have had an allergic or unusual reaction to.

Any other useful information:

- who you want to make decisions for you if you can't make them yourself;
- contact details for your main care person;
- information about your dependents — who is caring for your children etc.;
- your GP's name and contact details.

Consent and Power of Attorney

It is important to remember that even though you are in hospital, you are still in control of what happens to you. Hospitals exist as a service to provide you with care, to help pinpoint exactly what is causing the problems or discomfort you are experiencing and to offer treatments to help correct these problems.

It is entirely up to you, or to the person you nominate to make decisions for you if you cannot make them yourself, how much or how little investigation and treatment you accept.

All tests and treatments should only be provided after you or your nominee has given an informed consent. This consent is usually in the



form of a written statement by you that you have had the reasons for the investigation or treatment explained to you, along with any complications which might occur as a result. You also have the right to an explanation of any alternatives which may be available so that you can make a choice.

Hospitals are busy and confusing places sometimes. You may find that someone puts a form under your nose on the way to a test or as they are preparing to give you a treatment and asks you to sign it as a consent. Even though it might seem that you are causing a problem by insisting on a clear explanation, it is your right to delay the treatment or test until you have had a clear explanation of what it is for, what it consists of and what complications might follow. The choice to proceed is always yours and unless you are in a life-threatening situation, a delay that gives you time to make an informed choice should not be a problem.

If you are too sick to make your own decisions, you can nominate someone to decide for you. There are forms available from your AIDS council which give medical power of attorney to the person you nominate. You can always remove this if you feel better later and have the energy and capacity to make your own decisions again.

If you are giving someone your medical power of attorney, make sure that you have a talk with them about your wishes. These conversations are often difficult as they involve discussing what might happen if you are about to die, but they are worth having as they really help your nominated person if they are asked to make difficult decisions on your behalf. It's usually easier to have these discussions while you are well. This might also be a good time to make sure that you have a will so that there is no confusion about who gets what after you die.

Some of the things you might want to discuss with your nominated person are:

- any tests or treatments you wouldn't want;
- how you would decide when to stop tests and treatments;
- how you would like to be treated by staff;

- who you would like to have care for your children or other dependents;
- what you would like to have happen at your funeral?

Who's who?

Hospitals are complicated places full of procedures, policies and systems. But they are also places full of caring staff who will go out of their way to make you feel comfortable.

It is sometimes hard to figure out who is responsible for what in a hospital. Although all the disciplines work together in a 'multi-disciplinary team' they all usually exist in quite separate hierarchies and structures and are accountable through these structures. Here is a very brief and general summary of who does what at the level of the hospital ward.

Medical staff

Specialist

You are usually admitted to the hospital under one specialist. His or her name is usually written on a card over your bed. The specialist is the overall co-ordinator of your medical care and visits you every one or two days.

Your specialist may arrange for specialists from other areas (skin, eyes, cancer, etc.) to see you about particular problems you are having that relate to their area of speciality.

Registrar

This is a senior doctor assigned to the ward or speciality area who is in training as a specialist. He or she is responsible for your day to day medical care and is usually on the ward every day.



Resident Medical Officer (RMO)

RMOs are doctors who have graduated but who are not yet registrars. They are assigned to wards for a few months at a time on a rotating system. They carry out day to day medical care but may not have much HIV/AIDS experience.

Medical students

Medical students visit wards as part of their university study. They are not officially part of your care team. They can learn a lot from having contact with patients but you have the right to refuse to see them if you wish.

Nursing staff

Nurses on the ward have different duties according to their level of training. If you are experiencing problems with the care you are being given, the Nursing Unit Manager has overall responsibility for care at ward level and should be able to help sort out any difficulties.

Nursing Unit Manager (NUM)

This person used to be called the charge nurse — she or he is the manager of the nurses on the ward and responsible for supervising your nursing care.

Clinical Nurse Consultant

This person has had considerable experience in a particular area of nursing and is responsible for co-ordinating care and training in that area.

Clinical Nurse Specialist

This person is a registered nurse with specialist experience in a particular area of nursing.

Registered Nurse

This nurse has a degree or three year training in nursing and is responsible for patient care.

Enrolled Nurse

This nurse has completed a one year course and can carry out personal care (bathing, dressings etc).

Ancillary Staff

The hospital has a range of other staff members who are there to assist with your care.

Social workers

Social workers are responsible for providing counselling, support for family and friends, information on social services and referrals to community services.

Dietitians

The dietitian is a very important person to get to see whilst you are in hospital. He or she can help with advice on what to eat when you go home and can arrange for special diets from the hospital kitchen. Hospital food can be a bit difficult to get used to. If you just settle for the stated menu you can risk quickly losing any weight gains you may have had to fight to make at home. The dietitian can help you get a good range of food types and can tailor the meals and snacks to your needs.



Physiotherapists

Physiotherapists help you to stay as mobile and as fit as possible. They also help you to recover from chest infections and to avoid other complications.

Occupational Therapists

Occupational Therapists help you to maximise your independence and mobility. They can help you to design strategies to maintain your treatment regime and your personal safety at home.

Other staff

There are a range of other staff — ward clerks, medical records staff, porters, cleaners, catering staff — who are all there to help you.

What level of service can you expect?

Encountering this range of people in hospital can be confusing. It's OK to ask someone who they are and what they want when they come into your room or bed area on the ward. Hospitals are busy places but you have the right to expect that you will be treated as an individual. You have the right to expect polite, friendly and efficient service. You also have the right to raise problems you are experiencing and have your complaints and concerns dealt with in a professional manner.

If you are not getting the service you need or you are not happy with any aspect of your care, talk to the Nursing Unit Manager. If that doesn't change things, ask to see the Assistant Director of Nursing or Nursing Supervisor. The Social Worker can also assist in working out any service difficulties you are having. Some hospitals have consumer advocates. These people can be very useful in assisting you to tailor the hospital service to your particular needs.

Family & friends

Being admitted to hospital can be quite a stressful experience. Not only are you sick and therefore worried about whether this means that you have advanced to another level of illness, but you may also lose the control that you have over organising the way family and friends are positioned around you.

At home, it is usually up to you to decide whether you mix family and friends. Every person has a different set of relationships with family and friends. Many gay men, for instance, maintain a separation between their gay friends and their biological family. If you grew up in another city or town, your parents and brothers and sisters may not know many of your friends.

In hospital, everyone gets to meet each other and this can sometimes cause extra tensions. Your parents or other family members may want to take control of decisions. Your family and friends may find that having you in common is not enough to ensure that they get on with each other. If you have children, they may find it particularly disturbing to have you in hospital. They may also find it difficult to be cared for by someone else.

This may not be the best time for the people who are important in your life to find out that you have HIV. If you are sick, you may not have the energy to deal with family members or friends who are distressed to find that you have HIV/AIDS. Hospital social workers are experienced at providing support at these times and it may be useful for you to arrange for the social worker to see your family members or friends when they visit.

Hospital admissions often happen with little warning and it is often difficult to keep your diagnosis from visitors, particularly if you are being treated in a ward with other people with HIV/AIDS. Obviously, who you tell and when you tell them is up to you. Hospital staff are required



to keep your diagnosis confidential and cannot give your visitors information about your diagnosis or HIV status without your consent.

You need to let staff know what they are able to tell family and friends and, more particularly, who they should not be giving information to so that this can be recorded in your medical notes. If you are being treated in an AIDS unit, your confidentiality may be accidentally breached by staff when family or friends telephone to see how you are. If you have special needs for confidentiality, you will need to discuss these with the Nursing Unit Manager so that accidental disclosure can be avoided.

Getting some rest

One of the most important things you need when you go to hospital is rest. Unfortunately this can be difficult to achieve. You may find that you have a constant stream of visitors and that family members and friends arrive from far away to spend time with you. If things are getting out of hand, it might be helpful to put someone, like your partner or best friend, in charge of traffic. They, rather than you, could be the person who people telephone to find out how you are and to arrange to visit. In this way, you are left to rest and concentrate on getting well.

You can also arrange with hospital staff for periods without visitors during the day so that you can sleep. Unless you are in a single room, nights in hospital often allow for only broken sleep as the people around you require care. You may need to supplement this with naps during the day. Remember, it's OK for staff to turn people away or ask them to come back later. It can be very tiring being the constant host as visitors fumble around for things to talk about as they sit beside your bed.

Try to remember that people usually mean well. They aren't to know that a fruit basket isn't the ideal present for someone with diarrhoea that won't stop.

Don't be afraid to be clear about what you want. If you have children, it might be more stressful for you if you can't see them every day but you may not want to see people you do not feel close to. You can talk this over with your carer or with the nursing staff so that you get the right balance of rest and support.

Eating well

It's sometimes hard to eat well in hospital but it's important for your recovery to try to eat as much as possible. Ask to see the dietitian and get them to map out a plan with you. You may be surprised to find a wide variety of different foods to eat and you may find that you can manage four or five light meals each day rather than three big ones.

You can also put your visitors to good use, sending them out for takeaway from your favourite restaurants. Try to have a stock of the things you like to eat in your locker or in the ward fridge and get visitors to replenish it regularly.

Talk to the dietitian about extra food like yoghurt or snacks.

Getting some support

Being in hospital can be quite stressful. You may have developed good coping mechanisms outside hospital — things which allow you to have your HIV/AIDS diagnosis in some perspective. Being in hospital means that you and everyone around you, are focused almost entirely on your HIV disease. It may be harder to maintain your usual balance and you may experience a range of distressing thoughts and feelings.

Hospital social workers are there to provide support and counselling. They, like other counsellors, are required to maintain confidentiality. You can ask to see a social worker either whilst you are in hospital or after you go home. You can also ask for a referral to a volunteer emotional support program or to an AIDS council counsellor, HIV/AIDS peer support group or for spiritual support.



Planning to leave hospital

Nursing staff and social workers can also help you plan for your departure from hospital. This is called discharge or separation planning. Staff can arrange for home care, counselling, Meals on Wheels, community nursing and any other services you need to make it more comfortable to be at home.

It is good to start the discharge planning as early as possible. Some people like to start from the time of admission. Some community services need a few days notice of your need for their services and some like to visit you in hospital to do an assessment and design services to better meet your needs.

Principles of best practice

- Streamlined admission procedures for regular patients
- Accurate and available medical records
- Informed consent for all procedures
- Maintenance of confidentiality
- Support for family and friends
- Non-judgmental understanding of diversity of support needs of people with HIV/AIDS
- Recognition and acceptance of cultural and spiritual differences
- Day treatment facilities which take account of the needs of people with chronic illnesses in relation to work commitments etc
- Discharge planning and a strong link with community services

*principles of
best practice*

hospice & palliative care

HOSPICE & PALLIATIVE CARE

Hospice

a place or service which provides care and support for people with terminal illnesses and for people who are dying

Palliative Care

a health care speciality which aims to relieve the pain and discomfort of people with terminal illnesses



symptom relief
counselling and support
pain free environment

Being referred to a hospice or palliative care service was often a stressful event for people with HIV/AIDS because they often thought of these services as the last stage of life. People often thought that their doctor had given up on them if they referred them to the hospice and that the hospice was a place that people went into but didn't come out of.

That is not to say that people do not die in hospices. They do. Hospices are often much calmer places than hospitals and hospice staff are trained to provide people who are dying with a calm and pain free environment.

Hospices and palliative care services also provide care for people who are not about to die. People with HIV/AIDS are referred to palliative care services at any stage of their illness that might require attention to



issues of pain management or symptom relief. People use hospices as a place for occasional rest periods and to give their carers a break. Some go to hospice following a visit to the acute care hospital to make sure that they are fully recovered and to build up their strength.

Palliative care services now extend well beyond the walls of the hospital or hospice and can be an important part of home-based care and support.

Hospices can provide:

- grief & loss counselling;
- terminal care;
- respite care (rest periods);
- recuperation.

Palliative care services can assist with:

- pain management;
- symptom relief;
- counselling & support;
- specialised equipment for home care.

Hospice and palliative care services can be integrated into your general care as a person with HIV.

Your GP, hospital doctor, social worker or community nurse can make a referral to hospice or palliative care services if you want assistance with pain relief, symptom management or hospice care. You can also refer yourself.

If you would like to know more about what a hospice is like, or what services they can offer, maybe you could visit the one you would be most likely to use and find out a bit about what they have to offer. This doesn't have to be a morbid exercise. Think about taking a friend or counsellor along for support. Maybe if you know a bit about what they do it won't seem as frightening if you have to use them.

Be prepared for the fact that there are people there who are in the final stages of their lives, but they aren't the only ones there. There are lots of people just getting on with life and using the hospice services when they need them.

People who work in hospice and palliative care services are generally a very caring and practical bunch. They have seen lots of people with terminal illness and some of the 'down to earth' approaches that their clients take have rubbed off on them. They generally tell it like it is and often have a great sense of humour. Don't be afraid to be yourself.

What can you expect if you are using a hospice or palliative care service?

- Appropriate management of pain and symptoms

These services specialise in pain management, making creative use of a wide range of pain management approaches including, but not restricted to, pain relieving medications. You can expect that you will not be in constant pain and that they will work hard to balance your need for pain relief with your desire to be as conscious and functional as possible.

You can also expect that they will assist you in minimising discomfort from symptoms like nausea (feeling sick in the stomach or like you are about to vomit), headaches, nerve pain and other symptoms.

- An understanding of the particular pain control needs of injecting drug users with HIV/AIDS

Some injecting drug users find that they need higher doses of pain relief medication to relieve pain because their system has developed a higher tolerance of some medications. You can expect that hospice and palliative care services will understand this and not make negative judgements about injecting drug users.

- Support for your family and friends



Most hospice and palliative care services will have an interest in providing support for the people around you. This lightens the load on you and gives your family and friends the support they need to care for you.

Support is also available to your family and friends after your death if they want.

Principles of best practice

- Understanding of the needs of people with HIV/AIDS
- Ability to provide services in conjunction with acute care and treatment
- Acceptance of patient's right to pursue complementary therapies
- Provision of an environment of rest and support
- Respite care facilities
- Counselling and support services for family & friends
- Good links with other community services
- Ability to extend services beyond the hospice
- Pain management expertise and a willingness to explore a broad range of pain relief and symptom control mechanisms
- Non-judgmental attitude to pain management
- Acceptance of the wide range of spiritual beliefs and cultural practices of patients

*principles of
best practice*

BEING INVOLVED IN RESEARCH & CLINICAL TRIALS

Participation in

research has been an important part of Australia's successful response to HIV/AIDS. Australia has participated in many important international clinical trials of new HIV treatments.



social research
new treatments
participation
clinical studies

New drugs or combinations of drugs are usually tested in clinical trials. A group of people are recruited and their response to the drug or group of drugs is studied over time. Participation in research has been an important part of Australia's successful response to HIV/AIDS. Australia has participated in important international clinical trials of new HIV treatments. Social research has also provided important information for the design and review of services for people with HIV/AIDS and their carers.

Informed consent

One of the most important basics about participating in clinical research is that you are given appropriate written and verbal information at the beginning of the trial, before any of the initial work (eg. blood tests, weight, etc.) are undertaken. This is called getting your informed consent. It will involve a form for you to read and sign, explaining what the procedures are, as well as the purpose of the research, its potential benefits, and any potential risk. Don't just sign on the dotted line, though, if you are not clear about anything. Talk to the person or people running the study to be sure you know everything you need to know.



Remember: you're free not to participate in any study. Your doctor might think it is important, but it is your absolute right to decline for whatever reason, and saying no cannot compromise your health care or relationship with your medical care providers.

Phases of research

There are different kinds of studies, and different reasons you might want to participate in clinical research. Some agents may be promising in test tubes, laboratories or very small numbers of people, but they might not be well-tested in people yet. This is usually called a Phase I or Phase I-II study, and means the drug is still pretty experimental. Still, you might want to participate in such research because you believe it is important or useful, or offers an approach which is attractive to you. These trials might have more risk, so this should be carefully considered.

When more about a drug is known, it is usually what is called a Phase III study. In these trials, quite a bit might be known about the drug, including possible side effects. It may even be licensed or available overseas, or have been used in other diseases and conditions. One potential advantage of Phase III studies is that you can get access to a new treatment, while ensuring that you are well-monitored. However, treatments in Phase III are often available outside of clinical trials, so you shouldn't sign up just because you think there's no other way of accessing it.

Placebo studies

In the past, studies of new HIV drugs were often designed to compare the new drug against no drug at all. People in the study were assigned randomly into two groups — one that got the new drug and the other that got a tablet that isn't the drug. This tablet is called a placebo. In trials like this, participants did not know until the end of the trial whether they were actually getting the real drug or not. This is called 'blinding'.

The researchers often did not know who was on the drug or the placebo either. This type of trial is called ‘double-blind’. This is the most rigorous type of trial design.

The down side for participants in placebo trials was the risk of not being on the new drug, or on any treatment at all if they were not also taking other drugs.

As the benefit of combination antiviral therapy for HIV infection has now been established, almost all trials of new drugs are now randomised studies of several (usually three) different open-label combinations with no placebo. Blinding is also less common.

Risks and benefits

The risks of being on new treatments are the potential side-effects and toxicities, for which you need to be monitored closely. You and your doctor therefore need to weigh up the likely benefit of the treatment against the possible drawbacks or disadvantages.

If you go into a study involving a placebo, you won’t know until the end of the trial whether you were getting the new drug or not. However, you should receive at the very least, the standard of care, which will normally be combination antiviral therapy, using already available drugs.

If you get sicker whilst you are on the trial, you will generally be taken off the trial once you reach the agreed level of change in your health set out in the trial protocol. If you were on the placebo, you will usually be offered the real drug from then on.

If the drugs being studied are already approved and the study is looking at different dose levels or drug combinations, the researchers will usually leave out the placebo group and everyone in the study will get some drugs.



Social research

In HIV/AIDS, social research is usually done to get a better idea of the needs of people with HIV, to judge the effectiveness of counselling or support techniques or services or, to describe how communities are affected by HIV/AIDS. Social research also studies HIV/AIDS risk behaviour in an effort to find better ways to help people maintain safe behaviour or avoid HIV transmission.

Social research studies usually involve techniques like questionnaires or interviews or having a researcher study a community or organisation to see how it operates.

Often in social research studies, you will not be told exactly what the researchers are trying to find out. This is because you might behave in a different way if you knew what they were studying and this could affect the results. It is generally possible for them to explain to you the area of interest that their study covers.

You as a research participant

If you are approached to participate in a research study, you might want to ask a series of questions to help you decide what to do.

- Will participating in this research benefit me?
- What harm could it do me?
- Who are the researchers? Have they done any HIV/AIDS research or research in a similar area? What organisation do they come from?
- What are they trying to find out?
- Do they have written information to give you that will help you make a decision to participate?
- Do they have an 'informed consent' form for you to sign? Is it clear and does it answer the questions you have?
- What will you have to do to participate? Is it very time consuming and does it involve lots of visits to clinics, etc?

- Will they reimburse any costs you incur by being involved in the study?
- Do they provide childcare and assistance with travel to and from trial appointments?
- What will they do with the information you supply?
- How will your confidentiality be protected?
- Will they tell you what they find out when the study is finished? How?

Issues specific to clinical research

- How is the study designed?
- Is there a placebo group?
- Do I get standard of care with available drugs?
- What are the side-effects of the drugs on trial?
- What happens if your blood test results get worse or you get sick while you are on the trial?
- How will that be defined?
- Are the ‘endpoints’ of the trial reasonable — will they let you off the trial and give you the drug if your results get worse or will they wait until you are dangerously sick?
- Will you then get the drug if you weren’t getting it as part of the trial?
- Do all subjects get supplied with the drug after the trial if it is shown to be effective?
- Are they offering some sort of support for people on the trial, such as counselling or group support?

Issues specific to social research

- Is there counselling available if the interviews raise issues which you want to look into further?

**Remember:**

- research studies are an important way to find things out which might improve HIV treatment and care;

and

- it's absolutely up to you whether you participate or not. No-one has the right to try to force you to sign up for a research study or to stay on a study you are not happy with.

Principles of best practice

PAGE

78

- **No coercion: the decision to participate in a study is yours alone**
- **No harm is done to participants as a result of their involvement**
- **Trial does not contain sections which provide a lower level of treatment than the current standard of care or treatment**
- **Realistic and ethical endpoints**
- **Confidentiality and privacy arrangements in place**
- **All potential participants provided with an informed consent form and explanation of the trial protocol in plain English**
- **Provisions are made for support and counselling for participants**
- **Adequate arrangements made for people whose health deteriorates whilst on the trail**
- **Data is properly analysed and results published**
- **Results communicated to the subject**

*principles of
best practice*

HIV/AIDS ORGANISATIONS AND HEALTH SERVICES

National Organisations

- ▶ **National Association of People Living With HIV/AIDS (NAPWA)**
02 9557 8825
www.napwa.org.au
- ▶ **Australian Federation of Aids Organisations (AFAO)**
02 9557 9399
www.afao.org.au

AIDS Councils

- ▶ **ACT**
AIDS Action Council of the ACT
02 6257 2855
- ▶ **NSW**
AIDS Council of NSW
Sydney
02 9206 2000
TTY* 02 9283 2088
Freecall 1800 063 060
Western Sydney
02 9204 2400
Islington
02 4927 6808
Wollongong
02 4226 1163
Lismore
02 6622 1555
Port Macquarie
02 6584 0943
- ▶ **NT**
Northern Territory AIDS Council
08 8941 1711
Freecall 1800 880 899
- ▶ **QLD**
Queensland AIDS Council
Brisbane
07 3017 1777
Freecall 1800 177 434
Cairns
07 4051 1028
Gold Coast
07 5575 6966
Sunshine Coast
07 5441 1222
Townsville
07 4721 1384
- ▶ **SA**
AIDS Council of South Australia
08 8362 1611
TTY* 08 8362 0306
Freecall 1800 888 559
- ▶ **TAS**
Tasmanian Council on AIDS,
Hepatitis C & Related Diseases
03 6234 1242



► VIC

Victorian AIDS Council
03 9865 6700
Freecall 1800 134 840
TTY* 03 9827 3733

► WA

Western Australian AIDS Council
08 9482 0000

* TTY services available for the hearing impaired.

Services for heterosexuals

HIV Positive Heterosexuals
(PozHets) 02 9515 3095
Freecall 1800 812 404
Straight Arrows
03 9276 3792 (men only)

PLWHA Groups

- ▶ **ACT**
PLWHA ACT
02 6257 4985
- ▶ **NSW**
PLWH/A NSW
02 9361 6011
Freecall 245 677
Positive Heterosexuals
02 9515 3095
freecall 1800 812 404
- ▶ **NT**
Positive Services
08 8941 1711
- ▶ **QLD**
Qld Positive People Brisbane
07 3017 1777
Freecall 1800 177 434
QPP Cairns
07 4051 1028
QPP Gold Coast
07 5575 6966
- ▶ **QPP Sunshine Coast**
07 5441 1222
- ▶ **QPP Rockhampton**
07 4926 4540
- ▶ **QPP Mackay**
07 4953 5071
- ▶ **SA**
PLWHA SA
08 8293 3700
- ▶ **TAS**
Positive People Tasmania
03 6234 1242
- ▶ **VIC**
PLWHA Vic
03 9865 6772
Freecall 1800 134 840
Positive Women Victoria
03 9276 6918
- ▶ **WA**
HIV/AIDS Peer Advisory Network
08 9482 0012



Major Hospitals with HIV Services

- | | |
|--|---|
| <ul style="list-style-type: none"> ▶ ACT
Canberra Hospital
02 6244 2222 ▶ NSW
Prince of Wales Hospital
02 9382 2222

Royal North Shore Hospital
02 9926 7111
Royal Prince Alfred Hospital
02 9515 6111
Sydney Childrens Hospital
02 9382 1111
Westmead Hospital
02 9845 5555 ▶ NT
Royal Darwin Hospital
08 8922 8888 | <ul style="list-style-type: none"> ▶ QLD
Royal Brisbane Hospital
07 3636 8111 ▶ SA
Royal Adelaide Hospital
08 8222 4000 ▶ VIC
The Alfred Hospital
03 9276 2000
Royal Melbourne
03 9342 7000 ▶ TAS
Royal Hobart Hospital
03 6222 8308 ▶ WA
Royal Perth Hospital
08 9224 2244 |
|--|---|

HIV Health Services

The Australasian Society for HIV Medicine (ASHM) publishes a comprehensive Directory of HIV, Hepatitis and Related Services.

The directory is available
Online at the ASHM website: <http://www.ashm.org.au>

OR
Hardcopy from ASHM 02 9368 2700.

