

# Ahead *of* Time:

*A practical guide to  
growing older with HIV*



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BUILDING OUR COMMUNITY'S  
HEALTH & WELLBEING

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Some information  
may be out of date

*Family*

*Travel*

*Faith*

*Future*



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*Disclaimer: The appearance of individuals in this publication does not necessarily indicate their sexuality or their HIV status.*

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# Introduction

## What is this book about?

The impact of HIV on our bodies and on the immune system as we get older is greatly affected by ageing. HIV affects each of us differently. Some people progress to symptoms very quickly, while others live for 20-plus years without any signs of immune suppression or symptoms. Each of us ages differently as well. How well we age and how the ageing of our bodies' impacts upon our health is unique to each of us. Therefore, HIV infection—coupled with natural ageing—creates added challenges for maintaining good health.

Ageing is a process that is natural for everyone—it's the process of growing older. The process of ageing includes a reduction in strength, endurance, speed of reaction, agility, metabolism, sexual activity and hearing acuity. The bones become more brittle, the skin drier and less elastic and the teeth may shed. Ageing is associated with, or responsible for, the ever-increasing susceptibility to disease and death that accompanies advancing age. There has been increasing discussion and great debate about what age this increased susceptibility begins, and whether this is very different for people who live with HIV.

*Process*

*Impact*

*Strength*

*Body*

*Debate*

*Natural*

*Health*

# Growing Older *with* HIV

Challenge

Strive

Adapt

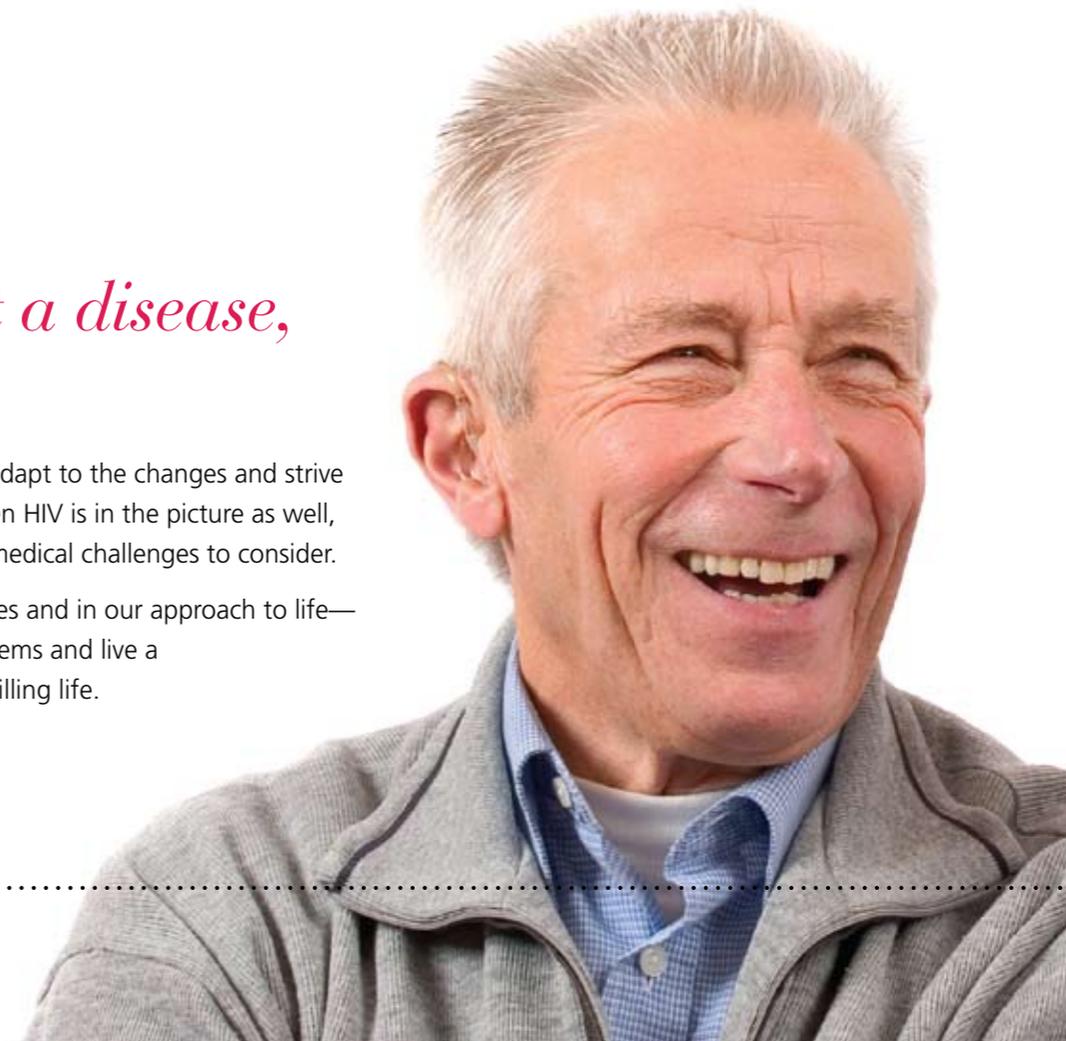
Change

Confront

*Ageing is not a disease,  
it's natural*

Although challenging, we can adapt to the changes and strive to get the most out of life. When HIV is in the picture as well, there are additional social and medical challenges to consider.

Managing change—in our bodies and in our approach to life—can help us work through problems and live a healthier, happier and more fulfilling life.





*“I stepped back, took a long hard look at my life and realised that although I wasn’t doing too bad for someone my age, I wasn’t as young as I used to be either.*

*I wasn’t enjoying partying like I used to and I could no longer keep up. The hangovers were getting worse, I wasn’t having as much fun, I was losing weight and I was going to the doctor more often. I realised things had changed...*

*Now I’m thinking more about what I want from life, I look after myself better, I’m making new friends and I’m having a different kind of fun.*

*Life is good!”*

When protease inhibitors (PIs) first became available in 1996, things radically changed for people with HIV. Combination therapy revolutionised antiretroviral (ARV) treatment and HIV is now increasingly considered for many people a chronic, but manageable condition. The ability to achieve and maintain higher levels of health—previously thought to be unobtainable—has allowed many to resume their lives, and live into older age.

Growing older can present challenges to us all, regardless of HIV status. But living with HIV and taking treatment can bring additional challenges. We will be the first generation of people with HIV to grow older. There's still a lot more research to be done on ageing and HIV to guide our journey, so in the meantime we need to be vigilant about our individual physical and emotional health needs.

Ageing might be confronting to some, but there are compensations: with age comes maturity, acceptance, understanding and a greater respect for health and life. With more life experiences we can have better coping skills, resilience, and a more robust sense of self. Recognising these benefits while accepting and adapting to the challenges can help us to achieve a happier and healthier future.

## The information in this booklet is designed to help you understand:

- The similarities between ageing and the courses of HIV infection and Acquired Immunodeficiency Disease (AIDS) suggest that HIV infection compresses the ageing process, perhaps accelerating co-morbidities (other illnesses) and frailty
- How age-related conditions, such as liver disease, kidney disease, cancer, menopause, cognitive function (thinking and understanding), bone mineral density (BMD), cardiovascular disease (CVD), and lipid and glucose metabolism (process by which food is converted into energy) may be aggravated and/or accelerated by HIV infection itself and by HIV treatments—referred to as Highly Active Antiretroviral Treatments (HAART); and as Antiretrovirals (ARVs)

- That Lypodystrophy (redistribution of body fat) is clinically significant because it is associated with the presence of several risk factors for cardiovascular disease such as diabetes, hypertension (high blood pressure), elevated total cholesterol (blood fats), and elevated triglycerides (fatty acids)
- That Aboriginal, Torres Strait Islanders, Pacific Islanders and Maori people are at higher risk of developing diabetes and cardiovascular disease at an earlier age
- That middle-aged women, who are HIV positive, have risk factors for cardiovascular disease related both to the menopausal transition and to the HIV infection
- That age is different from the length of time a person lives with HIV. For example, a 60 year old who is newly diagnosed may have very different experiences and levels of health than a 60 year old who has been diagnosed for 20 years—this person's experience and level of health may also be very different depending on whether they have commenced treatments or not.

Planning ahead, consulting with your doctor and staying in control of your health in the best way you can, is a practical way forward.

## What this book does not do:

The book is deliberately limited in its scope, and you are likely to find it does not answer all your questions about growing older with HIV. Because information about HIV is becoming much more complex and comprehensive, it is virtually impossible for any single resource to cover all the issues about ageing with HIV for all positive people. Some issues are currently being investigated or research is being undertaken to establish best practice.

These issues are well-covered by a range of existing publications which are available through AIDS councils and other organisations or online at [www.afao.org.au](http://www.afao.org.au). Towards the back of this booklet, there is a list of AIDS councils and PLHIV organisations where you can access counsellors and treatments officers.

This booklet does not replace your doctor. It is designed to give you an overview and help explain issues related to HIV and ageing. It is essential that you see a skilled and experienced doctor to manage your health.

*Don't try to read this booklet from cover-to-cover like a novel. You may feel overloaded, and some information is repeated in different sections, where it relates to specific issues.*

*Use the contents page and the colour index to skip straight to the sections that are relevant to you.*



# The Basics of HIV

**Over the past twenty-five years, there have been a number of changes in the ways HIV infection is understood and managed. These changes have led to great improvements in treatment and management of HIV infection and have greatly increased the range of options available.**

**Since the advent of Highly Active Anti-Retroviral Treatment (HAART) involving combinations of antiretroviral drugs (ARVs), deaths from AIDS have dramatically declined, and people with HIV taking treatments now have a much longer life expectancy.**

*Improve*

*Options*

*Body*

*There are a number of changes which have led to improvements in HIV treatments:*

- We have a clearer understanding of how HIV works inside the body
- The use of the viral load test measuring the amount of HIV circulating in your blood is now standard practice in Australia, Europe and North America. The results of this test can help in making treatment decisions. It can also show how well the treatments you are taking are working against HIV
- The use of genotyping and phenotyping assays (most commonly referred to as resistance testing) measure the likelihood of resistance to antiretroviral drugs and provide an indication of which drugs and combinations of drugs are working
- We have a clearer idea of the short- and long-term side effects sometimes experienced by people using these drugs, and how best to manage most of them.

*Resistance*

*Measure*

*Treatment*



# Medical Challenges *of* HIV

*Difference*

*Attitude*

*Support*

*Diet*

*Direction*

*Moderate*

*This chapter covers some of the health related issues faced by people with HIV as they grow older. It features what some people have done to make a real difference in their lives*

Improvements in HIV therapy are helping people with HIV live longer and more active lives. But living with HIV and taking HIV medications can add to the challenges of maintaining good health. Antiretroviral tolerability decreases with age. If you are starting therapy when you are older you may be more likely to experience side effects and laboratory abnormalities with antiretroviral drugs (ARVs). However, taking responsibility for your health can prevent conditions from becoming more serious.

Even though you receive your HIV care from a HIV specialist or clinic, it is still important to have a general practitioner (GP) or family doctor for health needs that aren't related to HIV. Many GPs also offer services that may not be available at your HIV clinic, but which you may need from time to time, such as support if you need nursing at home, mental health nursing, physiotherapy or podiatry.

As you get older you may need to coordinate your various health care needs and your doctor, PLHIV or AIDS organisations may be able to assist you to plan and organise this.

Keep your doctor informed about symptoms you may be experiencing, as well as possible interactions caused by other drugs, including any natural or complementary therapies you are taking.

Healthy habits and regular health maintenance will lead to less illness and a better quality of life.

Maintenance

Responsibility

## The Immune System

Ageing on its own inevitably results in a gradual decline in the functioning of the immune system.

People who first get HIV when they are older (say over 60) will, without treatment, progress to AIDS much faster on average than someone who gets HIV, say, in their 20s.

HIV is often described as having the impact of 'rapidly ageing' the immune system; although this effect is far more pronounced in untreated HIV infection. At this stage, the ongoing impact of HIV on the immune system—even in treated HIV infection—is not yet fully understood and is still being researched.

Improvements

Transition

## What can you do?

*Know about HIV treatments and when to start taking them*

Improvements in treatments for HIV have been accompanied with an increased life expectancy for people living with HIV. Prior to the advent of effective treatments in the 1990s life expectancy for people with HIV was an average of just over 10 years from the time of infection. Studies soon after the advent of effective treatments suggested that life expectancy for people with HIV infected before they were 40 was now somewhere between 8—15 years less than people without HIV infection. Recent studies with even more improved treatments show that the life expectancy of many people with HIV is now becoming quite close to the life expectancy of people without HIV.

### *Follow the recommended dosing instructions*

Those people who are likely to have close to a normal life expectancy are those who get diagnosed early, get the best treatments before their immune system is damaged and are able to follow the recommended dosing for their treatments without interruption for the rest of their lives.

Following the recommended dosing instructions means:

- taking the full dose of each drug as prescribed
- taking them at regular intervals as prescribed (if you have to take your pills once a day it is often good to associate taking them with a daily event such as reading the morning paper or having breakfast).

### *Some other tips to help with your pills*

- If you miss a dose then don't double up
- If you find you often get well into the day and can't remember if you've taken your pills or not, then get a pill box (dosette box) from your doctor which allows you to put your pills in an allocated slot for each day of the week—so you can go and check whether you've taken them or not
- Keep a backup or emergency supply of pills at the places you regularly spend a lot of time and keep them in a safe place, for example your workplace, partner's place, or a place you go to on weekends
- If there is going to be an interruption to your usual routine—plan ahead—to make sure you can still take your pills.

### *Know about therapeutic drug interactions and inform your doctor about all the drugs you are taking*

Prescription drugs, over-the-counter drugs and complementary/natural therapies can all interact with HIV treatments, and may affect how well both the HIV drugs and other treatments work. This includes the contraceptive pill and implants for women, with some HIV medications making the pill less effective as a contraceptive.



*Reactive*

*Plan Ahead*

*Habit*

*Reminder*

*Avoid any long treatments breaks — even missing one to two doses has been shown to increase the chance of resistance*

For a period of time when ARVs first became available there were doubts about how long these treatments would remain effective against HIV—and some of the earlier drugs were associated with serious side effects.

However, we now know that ARVs can work for the long term and that there are a lot more treatment options available should side effects become a problem for one drug.

It also used to be common for people with HIV to take a break from their treatments. We are now more certain that staying on treatments all of the time is more likely to produce the best long-term outcome.

*Know about recreational drug interactions*

Recreational or party drugs can harm your health and the effects can be harmful for both the short and longer term.

The use of ecstasy, crystal/ice and other types of methamphetamines may cause dangerous, even fatal interactions with some types of HIV treatments, as the HIV drugs slow down the body's elimination of recreational drugs.

Some drugs interact with HIV treatments, leading to treatments that don't work as well or have worse side effects.

Using ecstasy, crystal/ice and other types of methamphetamines and other party drugs is likely to further suppress your immune system, making it more difficult for your body to fight off disease. Heavy drinking

can further suppress your immune system and may slow down your recovery from infections.

In addition to the drugs, the partying lifestyle, itself, can weaken your immune system. Staying up for long periods of time, not eating enough, or not eating the right foods can damage the immune system of any person, even if they are in great health.

Methamphetamines and ecstasy can also make eating difficult, which can be a problem for people who need to take treatments with food.

Heavy alcohol use can also have potentially serious consequences for people taking HIV medications and may affect how well you adhere to your HIV medications.

*Complete the checklist for healthy ageing at the end of this booklet and have a discussion with your HIV doctor and other specialists you are seeing*

There is a lot of research that shows things like smoking, having a lot of stress in your life, not getting enough exercise, not getting enough sleep, depression, and being socially isolated are bad for your health. One of the body's systems that may be affected is your immune system. Following the tips for healthy living is not just good for your overall health, but is probably good for your immune system as well.

*Best Outcome*

*Checkups*

*Health*

*Interaction*

### *Speak to your doctor about getting vaccinated against:*

- hepatitis A
- hepatitis B
- bacterial pneumonias
- influenza (Flu)—a yearly vaccine.

These infections can cause more difficulties with adherence to HIV treatments, as well as contribute to the rapid progression of the infection in people with HIV, so it is important to speak with your doctor about the range of vaccinations that are now available.

You can also speak to your doctor about information on other vaccinations available, such as vaccines for the human papillomavirus (HPV); the virus that may cause genital warts, cervical cancer and anal/penile cancer (although this may not be effective if you have already been exposed to HPV).

You should also speak to your doctor about vaccinations that you may want to avoid. For example, if you are planning on travelling, you should speak to your doctor about the vaccinations that you can safely have and leave plenty of time to get them.

## Cardiovascular Health

Cardiovascular disease (CVD) refers to a group of diseases and illnesses of the heart and blood vessels and includes:

- coronary artery disease (narrowing of the arteries that supply blood to the heart, which can lead to chest pain [angina] or heart attacks)
- cerebrovascular disease (strokes and other problems with blood vessels in the brain)
- hypertension (high blood pressure)
- peripheral vascular disease (blocked blood vessels in the legs).

Changes in blood lipids (fats) are associated with both HIV infection and ARV treatments and with increased risk of cardiovascular disease. Both HIV infection and ARV treatment can change the cholesterol levels in your blood and increase the risk of cardiovascular disease.

**Low density lipoprotein (LDL)** is also known as bad cholesterol because it can add to the build up of plaque in your arteries and increase your risk of getting coronary heart disease.

**High density lipoprotein (HDL)** is also known as good cholesterol because it helps to protect you against coronary heart disease.

As people with HIV live longer, cardiovascular disease is becoming an increasingly significant problem for people with HIV. It is now perhaps one of the most common causes of death for people with HIV.

The original goal of HIV management was to target the HIV virus itself, and thus reduce HIV viral load to undetectable levels. However, as awareness of the increasing problem of cardiovascular disease has grown, many doctors now describe an important secondary goal in HIV management is to try to reduce the risk of cardiovascular disease in people with HIV.

There are many risk factors for cardiovascular disease. They include:

- smoking (tobacco and marijuana)
- excessive alcohol consumption
- amphetamine use
- high blood pressure
- poor diet
- insufficient physical activity
- obesity and abdominal fat accumulation (as measured by waist circumference and your BMI [body mass index])
- blood lipid abnormalities, for example,
  - high total cholesterol (> 5.2 mmol/L)
  - high LDL (>4 mmol/L)
  - low HDL (<1.0 mmol/L)
  - high triglycerides (> 2.0 mmol/L)
- impaired glucose metabolism
- insulin resistance
- diabetes (fasting glucose >7 mmol/L).

The risk factors identified above however are ones that you can change through appropriate treatment or by making lifestyle changes.

However, risk factors that you can't change include:

- older age (>45 for males and >55 for females)
- male gender (women tend to lose any protection from CVD once they become post-menopausal)
- being HIV positive
- family history of CVD.

Some ARV treatments are associated with changes to blood lipids (fats) and some of the older HIV drugs increased the risk of diabetes—both of which increase the risk of cardiovascular disease.

Studies show that HIV measurably adds to cardiovascular risk if you also have other risk factors present, but without these other risk factors being present the impact of HIV on increased risk is far less noticeable.

This is why increasing attention in the care and treatment of all people with HIV also focuses on preventing cardiovascular disease.

## *What can you do?*

### *i) Attitudes and understanding*

People with HIV generally understand the need to take HIV treatments to prevent advanced HIV disease. As awareness of the link between HIV and cardiovascular disease grows, we now need to have as much awareness about the need to reduce our risk of getting cardiovascular disease.

Understand that **now is the best time to act!**—not delaying lifestyle changes until you have symptoms or until you are at high risk.

It is never too soon to start dealing with risk factors—the sooner you do, the more you are reducing the risk of developing cardiovascular disease. For example:

- stopping smoking results in large decreases in your risk factors within the first year
- if you are overweight, each kilogram you lose will immediately reduce your blood pressure.



## ii) *The menu of things you can (or may need to) do*

### **Regular monitoring.**

As part of regular monitoring you should be getting your blood pressure taken and your blood lipids and blood glucose levels done periodically (usually bloods are taken after overnight fasting).

Both your lipids and glucose levels should be measured before starting or changing anti-HIV treatments. If you aren't aware that these tests are available, ask your doctor about them.

You might also want to initiate a discussion about your cardiovascular risk with your doctor.

### **Stop smoking.**

If you smoke then stopping smoking is the single most important thing you can do to reduce your risk of cardiovascular disease. There isn't any debate about it not being easy! Quitting smoking can be one of the most difficult, yet rewarding things a person can do:

- most smokers' say they would like to quit, and many have tried at least once. Some are successful the first time, but many other people try a number of times before they finally give up for good
- if you are thinking of stopping smoking, or have made the decision to stop, it is important to choose a method that suits you and your lifestyle
- bear in mind that research has shown that combination approaches offer the best long term success rates. So for example, you might decide to cut down your smoking gradually; however, if you cut down AND use nicotine replacement therapy (e.g. nicotine patches, tablets, gum etc.) then you are more likely to succeed than if you only use the cutting down method

- you can talk to your GP for support and suggestions as well. She or he can advise you of new and emerging pharmaceutical therapies and treatments that could make quitting even easier
- for the cost of a local call from anywhere in Australia, the Quitline, contactable on 131 848 or 137 848, provides advice and assistance to smokers who want to kick the habit. The Quitline can help smokers plan their attempt, give advice on different techniques, provide information on the availability of stop smoking programs and supply written material on how to quit.

### **Reduce alcohol intake.**

Excessive alcohol use is known to be associated with high blood pressure. There are also studies however, that indicate that a small glass of alcohol each day may reduce your risk of heart disease.

### **A diet that's good for your heart.**

The main features of a diet that is good for your heart are:

- eat a variety of foods
- include vegetables, wholegrains, fruit, nuts and seeds every day

- choose healthier fats:
  - *less than 10%* of calories should come from saturated fats such as beef, beef fat, veal, lamb, pork, lard, poultry fat, butter, cream, milk, cheeses and other dairy products made from whole or 2 percent full-cream milk, coconut milk, coconut oil, palm oil and palm kernel oil and cocoa butter
  - most fats in your diet should come from sources of polyunsaturated and monounsaturated fats, such as fish, nuts, seeds and vegetable oils (e.g. salmon, trout, herring, avocados, olives, and walnuts; and liquid vegetable oils such as soybean, corn, safflower, canola, olive and sunflower).
- try to limit sugary, fatty and salty take-away meals and snacks
- drink mainly water.

Detailed dietary information is available from the Heart Foundation [www.heartfoundation.org.au](http://www.heartfoundation.org.au) and HIV doctors can refer you to an experienced HIV dietician.

**Maintain a healthy weight.**

Weight loss tends to reduce your levels of LDL and VLDL (the “bad” fats) and raise your levels of HDL (the “good” fats). Weight loss also reduces blood pressure.

**Increase your physical activity.**

Aerobic exercise also lowers LDL and VLDL levels and increases HDL levels. It can also help lower your blood pressure. Exercise—even at a moderate level—improves your cardiovascular health. Note that exercise such as weight lifting, which is anaerobic does not have the same benefit.

The recommended levels of exercise is 30 minutes of moderate activity per day (2.5 hrs per week) on five or more days of the week.

Another way to monitor your activity is to walk 10,000 steps a day if you are at low to moderate risk of cardiovascular disease, and 15,000 steps a day if you are at

high risk. Your doctors can give you advice about getting a pedometer to count your number of steps.

If walking is a problem for you there may be low impact exercise classes you can access close to where you live, such as aqua aerobics.

**Get elevated lipid (blood fat) levels treated where appropriate.**

There are different options that may be tried to lower your lipid levels if you are concerned that they are high:

- where your HIV treatment regime includes protease inhibitors or other drugs that have been shown to be associated with higher levels of blood fats, it may be possible to change your treatment regime. This, accompanied with dietary modification and exercise, may be tried first
- if this first step doesn’t work, or if your lipid levels are very high, there are a number of different

classes of lipid lowering drugs that decrease total and LDL cholesterol levels and lowers cardiovascular disease risk:

- Statins: are used to reduce total and LDL cholesterol levels in HIV positive patients (*artovastatin and pravastatin are preferred because they interact less with ARVs than other statins*).
- Fibrates: can be used to decrease triglyceride levels and when used with statins, they may have an additional effect (*gemfibrozil, and fenofibrate*).

These lipid-lowering drugs may interact with ARV treatments, so it is important that whoever is prescribing them knows about all of the medications you are currently taking. (There are initial small studies showing some benefit from these drugs in people with HIV, but longer larger studies are still being done).

**Get hypertension (high blood pressure) treated appropriately.**

Exercise and diet modification may be attempted first when mild hypertension is observed. If the hypertension persists or is severe, then treatment will usually be recommended.

There are a number of different classes of drugs that may be used in combination. Some are not recommended because of known interactions with ARV treatments. It is important that whoever is prescribing these medication knows about all the drugs you are on.

Sometimes, after getting your blood pressure under control and putting in place the necessary exercise programs and having lost weight, it may be possible to reduce the dose of anti-hypertensive drugs or stop taking them altogether.

**Due to your increased cardiovascular disease risk, the overall goal may be to change, but not stop, your HIV treatments.**

There is still debate and controversy about the exact HIV treatment guidelines for older people who are at significant increased risk of CVD. Some large studies have shown that protease inhibitors (PIs) are associated with an increased risk of cardiovascular disease when other risk factors are also present.

However, there are also studies showing that untreated HIV infection is significantly associated with increased cardiovascular risk (i.e. HIV and the body's response to it on their own lead to increased risk).

There are also studies that show a break from your treatments is associated with an increased risk of events that are bad for your health. At the moment the strong consensus is that the benefit of staying on treatments—which are modified for your cardiovascular risk—far outweighs stopping or not starting treatments because of the cardiovascular risk associated with some anti-HIV treatments.

### *iii) The process of changing*

**You don't have to change every risk factor now: do it in steps.**

We've all done those new years' resolutions about a new healthy life starting on January the 2nd. Trying to make a dozen changes at the same time isn't usually a successful strategy. Make a priority list—work out what's achievable and realistic.

**The first step is often picking a date.**

There's often a process we go through in our minds about making changes. We know we should, but we keep delaying it until tomorrow. Sometimes an important process is picking a date further away—and saying on this date I'll start to do X—and working yourself up to begin implementing a change on that day.

**Work out what's most important.**

*'But if I stop smoking I'll put on weight'.*

How often have we heard excuses? Smokers on average do not weigh less than non-smokers. Sure, on average some people initially put on weight when they stop smoking, but in the longer term, they are in fact likely to weigh less than if they hadn't stopped smoking. Stopping smoking is the most important thing you can do.

**You don't have to do this without help.**

Think about the process of deciding to go on treatments and then taking your treatments every day. You had a doctor helping you and a lot of information resources available. It was a decision you were making for the rest of your life.

The decisions you make about reducing your risk of cardiovascular disease are becoming just as important, and there are often a host of programs, services, organisations, groups and health practitioners that are available to help you.

All the evidence suggests that working with others to implement lifestyle changes has more chance of long-term success than doing it on your own.



## Cancer Screening

People with untreated HIV can be at higher risk of a wide range of infection-related cancer types. The ageing of the population with HIV means that even in treated patients, cancer may soon become one of the leading causes of morbidity (illness) and mortality (death) in people with HIV. Recent research shows that immune deficiency is the probable explanation for the increased cancer risk; suggesting a broader than previously appreciated role for the immune system in the prevention of cancers related to infections

For men who have sex with men, cellular changes in the genitals and anus, including those caused by the human papillomavirus (HPV)—the virus that causes warts—sometimes leads to anal cancer. This is more common in HIV-positive men and especially those with a low CD4 count.

For women, abnormalities in cervical cells, including those caused by HPV, and cervical cancer can occur regardless of HIV status. They are more common in women with HIV, and can be more invasive.

## What can you do?

### *Cancer prevention is possible*

Maintenance of optimal immune function through HIV treatment will prevent many HIV-associated cancers. How high we should aim in terms of CD4 cell counts is an unknown factor at this stage, but will hopefully be answered by currently planned studies of the early treatment of HIV infection.

### *Smoking cessation— the other top priority*

Smoking can weaken your overall immune system—placing people with HIV who smoke at greater likelihood of getting some opportunistic infections and AIDS-defining illnesses in patients with a low CD4 count.

Smokers who are HIV positive are much more likely to develop many of the conditions linked to smoking than those that are HIV negative, with most of these conditions rarely occurring among non-smokers.

People with HIV are also at significantly increased risk of heart disease, with HIV infection and ARV treatments already contributing to this increased risk. HIV-positive smokers are also at increased risk of different kinds of cancers.

### **If you smoke, then quitting is the single most effective way to improve your health.**

Screening for the early detection of cancer is the same as it is for the general population, except for:

- men who have sex with men (those over 40 should talk to their doctor about getting an anal cancer check)
- women with HIV should get a pap smear every year.

Speak to your doctor for more information about these and other types of cancer you may be at higher risk of, and about whether a vaccination for HPV would be effective for you.

## Body Shape Changes

Historically, HIV disease has been associated with changes to body shape.

Prior to HIV treatments being widely available, people with advanced disease often developed what was called ‘HIV wasting syndrome’ which was associated with a rapidly ageing appearance and the loss of subcutaneous fat—most visible in the face. Plastic surgeons suggest that the loss of this subcutaneous fat in the face plays the biggest role in the normal ageing of the face.

In the late 1990s a number of people on treatments developed a syndrome known as ‘lipodystrophy syndrome’. This syndrome was particularly associated with lipoatrophy (the loss of fat in the face and the limbs). This pronounced lipoatrophy was shown to be particularly associated with some of the treatments used to treat HIV, particularly d4T (stavudine) and less commonly AZT (zidovudine) and ddI (didanosine).

HIV treatments that are most associated with lipoatrophy of the face and limbs are now rarely used. As a result the more severe effects of lipoatrophy are rarely seen in people who commenced treatment this century.

## *What can you do?*

### *Regularly have your health monitored with your GP*

As we become older the number of minor and major illnesses we are at risk for increases. Having HIV both adds to the number of illnesses and to the risk of getting some illnesses. That is why regular monitoring is important—and many aspects of how you metabolise fats will be monitored for. Sudden visible changes in fat metabolism are now less likely to be related to HIV treatments but to some other underlying cause.

### *Change treatments — don't stop treatments*

If treatments may be contributing to lipoatrophy there are usually many other HIV treatment options available. Current medical advice recommends against taking any breaks from HIV treatments.

### *Cosmetic treatments*

Some cosmetic treatments became available and accessible well after lipoatrophy became a problem for people with HIV. Check with your doctor or local PLHIV association to see if you may now be eligible for subsidised cosmetic treatment for lipoatrophy.

### *A good diet and regular exercise*

You'll see recommendations for a good diet and regular exercise in every good living guide. People with HIV probably have more reasons to follow these recommendations—but unfortunately changing your diet or regular exercise can't replace the lost fat. Exercise can however build body mass in some areas where fat loss has occurred.



## Changes to Bones

Loss of bone mineral density (osteopenia), which can lead to more fragile and brittle bones (osteoporosis) is a common condition associated with ageing. Osteoporosis is most *common* in post-menopausal women.

People with HIV may be at increased risk for osteopenia and osteoporosis because:

- the lifestyle risk factors are more prevalent amongst people with HIV
- some antiretroviral medications are associated with increased risk
- HIV itself may cause metabolic changes that decrease bone mineral density (BMD).

Vitamin D is essential for bone health, because it helps:

- increase the absorption of calcium and phosphorous from the stomach
- regulate the amount of calcium in the blood
- strengthen the skeleton.

For Australians, the main source of vitamin D is from exposure to sunlight. Vitamin D3 is formed by the action of sunlight (UV light) on the skin. A deficiency of vitamin D can contribute to osteoporosis because without it, calcium will not be fully absorbed by your body.

Lifestyle risk factors for osteopenia include:

- smoking
- excessive alcohol
- a very low body weight
- low levels of physical activity
- lack of calcium and vitamin D in the diet
- low levels of oestrogen or testosterone.

## What you can do?

### Prevention is better than cure

Ways that you can decrease the risk of bone mineral density loss includes:

- making sure you have adequate levels of calcium in your diet: Low fat dairy products and leafy green vegetables are good sources of calcium. Calcium and vitamin D supplements are also available
- regular weight-bearing exercise: Walking, jogging, regular dancing and a host of other physical activities help to strengthen bones
- stop smoking, and avoiding excessive alcohol; both accelerate bone loss
- to get enough sunlight to produce vitamin D, a person needs to expose their hands, face and arms (around 15% of body surface) to sunlight for about 6–8 minutes, 4–6 times per week (before 10am or after 2pm in summer, for moderately fair people).

### Get appropriate screening of your bone mineral density (BMD)

If your doctor considers you to be at increased risk of osteopenia or osteoporosis, he/she will recommend you have an x-ray (called a DEXA scan) to assess your BMD. This will usually be recommended if:

- you have the lifestyle risk factors described above
- your medications include drugs that may increase the risk of bone mineral density loss (some protease inhibitors are considered to increase the risk)
- you are a post-menopausal woman with HIV
- you are over 65.

If you have these lifestyle risk factors and are concerned about their long term implications, you may want to initiate a discussion with your doctor about having a screening test of your bone mineral density.



## *Take more active steps, including appropriate treatment, if you are diagnosed with low BMD*

If you have low BMD then you are considered to be at increased risk of bone fractures (osteoporosis). In this case, treatments that may be recommended for you include:

- dietary supplements of calcium and vitamin D
- prescription drugs used to prevent and treat osteoporosis.

If you have osteoporosis and active symptoms (e.g. pain) then devices such as canes or even a walker can reduce the risk of falls and diminish pain. If pain is a problem, then exercise classes like aqua-aerobics may be available as an alternative to walking.

*Supplements*

## *Liver Health*

The liver is one of the most important and largest organs in your body. It has been described as the body's 'chemical processing plant'. It plays a key role in food metabolism and digestion, in producing immune system proteins and importantly for people with HIV, in the breaking down of prescription and other drugs, and alcohol.

Older age (even without HIV) is associated with decreased liver function.

A healthy liver is important to process medicines effectively, so if your liver has been damaged by drinking too much alcohol, you are more likely to experience side effects from HIV medications (especially if you have hepatitis).

The blood fat increases caused by some HIV medications can also be made worse by heavy drinking.

*Recommendations*

There are a number of reasons why people with HIV may be more likely to experience liver damage. These include:

- increased use of both prescription and over-the-counter medications, that can cause liver damage (especially paracetamol)
- increased incidence of hepatitis B and C
- increased levels of alcohol and other drug use.

Symptoms of liver damage include:

- pain in upper right abdomen or generalised abdominal pain
- fatigue
- nausea
- dark urine
- clay colored stool (faeces)
- jaundice (yellowing of the skin and white part of the eyes).

*Mediation*

## What you can do?

### Look after your liver by:

- Getting vaccinated against hepatitis A and B
- Get appropriate treatment if you have hepatitis B or hepatitis C. There are now treatments available which are having increasing success rates, and when treatment is successful it substantially reduces the risk of longer term liver damage
- Eating a healthy diet with lots of fruit and vegetables
- Avoid taking more than 4 grams of paracetamol in any 24 hour period
- Avoiding high fat food (deep-fried foods, fatty meats, processed vegetable oils etc.)

- If you have hepatitis or high levels of blood fats, you may have to cut down or stop drinking alcohol
- If you have liver disease, avoid high doses of vitamin A and high doses of iron. Some herbal therapies are liver toxic and some interact with HIV treatments in ways that are toxic to the liver.

Having HIV and hepatitis B or C can accelerate the progress of both infections and make both more difficult to treat. Hepatitis B is mainly spread through sex without a condom—particularly rough sex that draws blood, but can also be spread through sharing injecting equipment. Hepatitis C is mainly spread through sharing injecting equipment, but is rarely spread through sex.

- During sex, wash hands and toys and change condoms and gloves between partners
- If injecting, do not share any equipment, including spoons and tourniquets.

### Monitor your liver's health

You can have decreased liver function without any symptoms. Liver function tests (LFTs) are part of regular monitoring for people with HIV and results of LFTs in people with HIV are often outside of what is considered the 'normal' range. Such results do not necessarily mean you have, or are going to have, a huge problem with your liver. Your doctor will know when the LFT levels are something to be more concerned about.

### Let your HIV or Hepatitis doctor know about all of the drugs you are on

As we get older it is often the case that we are on more and more drugs for various conditions, therefore the chances of having drug interactions increases.



## Kidney Health

Kidney function gradually declines as you get older, but this rarely causes serious problems.

Diabetes (high sugar levels) and hypertension (high blood pressure) are the most common causes of chronic kidney disease. The rates of both of these conditions are usually significantly higher in people with HIV, and as a result, as people with HIV get older, chronic kidney disease may become more common.

Some HIV treatments have been linked to kidney disease:

- that link has been confirmed with indinavir—a drug now rarely used
- Tenofovir has the very rare side effect of Fanconi syndrome, a disorder of the kidney tubes in which certain substances normally absorbed into the bloodstream by the kidneys are released into the urine instead.

Kidney disease has often been called a *'silent disease'* because there are often few symptoms until the disease is severe.

Urinary infection, can also lead to kidney infection and kidney disease, particularly if it keeps recurring or is left untreated.

### Urinary Tract Infections (UTIs)

Urine is normally sterile, which means it doesn't contain any bacteria, fungus or viruses (micro organisms or germs).

Urinary tract infections (UTIs) are caused by these micro-organisms, which infect the urinary system by entering through the urethra or, rarely, from the bloodstream.

The most common culprit is a bacterium common to the digestive tract called E. coli (Escherichia coli)—which is usually spread to the urethra from the anus.

Other micro-organisms, such as *Mycoplasma* and chlamydia can cause urethritis in both men and women. These micro-organisms are sexually transmitted so, when these infections are detected, both partners need medical treatment to avoid re-infection.

The different types of urinary tract infection can include:

- **urethritis**—infection of the urethra
- **cystitis**—infection of the bladder
- **pyelonephritis**—infection of the kidneys.

Some of the symptoms of urinary tract infection include:

- wanting to urinate more often, if only a few drops (urgency)
- burning pain or a 'scalding' sensation on urination
- a feeling that the bladder is still full after urination
- pain above the pubic bone
- blood in the urine.

### Kidney infections are serious.

If infection reaches the kidneys, prompt medical attention is needed. In addition to the general symptoms, a person with a kidney infection can also experience:

- chills
- fever
- loin (lower abdominal) pain
- pain in the back.

## What you can do?

*You can decrease the risk of getting kidney disease by:*

### Living a healthy life style.

All the usual things reduce the risk of kidney disease:

- not smoking
- a healthy diet
- staying fit
- keeping a good body weight
- drinking lots of water—at least 6–8 glasses a day is recommended by kidney health organisations.

### Getting blood pressure tested and high blood pressure treated.

As well as lifestyle changes, there are many successful drug treatments for hypertension. Some anti-hypertensive medications also reduce any progression of kidney disease.

### Minimising your risk of getting diabetes and controlling blood glucose if you have diabetes.

Your doctor is often able to diagnose pre-diabetes. If it is diagnosed, it is sort of like the last stop café: both a warning and a great chance to make the lifestyle changes you need to make in order to avoid progressing to diabetes and all of the complications which follow from diabetes.

### Try to avoid urinary tract infections (UTIs), which can lead to kidney infection.

Urinary tract infections do occur in men, but are much more common in women, and may lead to kidney disease if they keep recurring—especially if they are not treated. Some suggestions for avoiding UTIs in men and women include:

- drinking lots of water and other fluids to flush the urinary system
- treat vaginal infections quickly (such as Thrush or Trichomonas)

- avoiding spermicidal products, particularly with a diaphragm contraceptive device
- avoiding constipation where possible
- practice good hygiene
- going to the toilet as soon as you feel the urge to urinate, rather than holding on
- emptying your bladder after sex.

### Getting kidney function monitored.

Because kidney disease often doesn't have symptoms, it needs to be monitored on a regular basis—particularly if you have risk factors for kidney disease.

It is beyond the scope of this resource to provide detailed information on the treatment of advanced kidney disease. More detailed information can be found at Kidney Health Australia [www.kidney.org.au](http://www.kidney.org.au).

## Blood Sugar, Insulin Resistance and Diabetes

Normally blood glucose is distributed to your body's tissues under the control of insulin. Glucose is then used as 'fuel' to meet the energy required by your body. In some cases, this process is disturbed and more insulin is needed for the tissues to take up glucose from the blood. The tissues are said to be 'resistant' to insulin, leading to a condition called insulin resistance; which is more common with increased abdominal fat, buffalo hump and in HIV-positive people on treatments.

Insulin resistance can lead to diabetes, a condition where blood glucose becomes quite high.

The incidence of type II, or mature onset, diabetes increases with age. As a result, as people with HIV live

longer due to improved treatments, the incidence of type II diabetes amongst people with HIV has significantly risen.

Independent of ageing, people with HIV are at increased risk of type II diabetes. Factors associated with this risk are:

- being on the protease inhibitor class of drugs for treatment of HIV
- a higher prevalence of some of the risk factors for diabetes amongst people with HIV.

It has not been demonstrated that HIV itself and its associated changes to the body directly result in increased risk of diabetes.

Preventing diabetes is important for people with HIV because it leads to increased risk of cardiovascular disease (for which people with HIV are already at increased risk) and in the longer term is associated with the development of a number of diabetes-related conditions.

## What can you do?

*Have your risk of diabetes regularly monitored by your GP in conjunction with your HIV doctor*

Factors associated with increased risk of diabetes are:

- use of protease inhibitors
- severe changes to body fat distribution
- hepatitis C infection
- age  $\geq 45$  years
- being overweight (Body Mass Index  $\geq 25$  kg/m<sup>2</sup>)
- having a waist measurement > 94cm for men & > 80cm for women
- physical inactivity
- a close relative who has diabetes
- a previously diagnosed metabolic disturbance
- a history of vascular disease

- indigenous, asian, indian background
- blood fat changes (low levels of HDL or high levels of triglycerides).

Your doctor will assess your risk by a history and by regular glucose tolerance tests.

*If you get diagnosed with “pre-diabetes” then it is time to act*

Pre-diabetes is where you have an impaired glucose tolerance test result, the levels are higher than normal but not high enough to be diagnosed as diabetes.

- without intervention or change, pre-diabetes will eventually become diabetes
- by acting now you can prevent or significantly delay pre-diabetes becoming diabetes
- a diagnosis of pre-diabetes may also lead to your doctor recommending you change your HIV medications.

*Know and implement the essential elements to preventing pre-diabetes progressing to diabetes*

Follow a healthy diet: for diabetes prevention this means reduced fat intake and eating a wide range of high fibre foods that have a low ‘glycemic index’ (see [www.healthinsite.gov.au/topics/Glycaemic\\_Index](http://www.healthinsite.gov.au/topics/Glycaemic_Index) for further information).

A pre-diabetes diagnosis is the perfect time to seek help from an experienced dietitian to develop a meal plan that will work for you.

Exercise regularly: either 30 minutes of moderate intensity exercise (brisk walking) at least five days per week, or three to four 20-minute sessions of vigorous exercise a week.

## Living with Diabetes & HIV

While diabetes treatment involves physicians, nurses, dietitians, and other health care professionals, self-care is crucial for managing diabetes. Good self-care includes diet, exercise, monitoring, and medications.

## What can you do?

*Diet, exercise, and smoking cessation*

- Exercise at moderate-intensity exercise for 2.5 hours per week (if approved by their clinician). Both aerobic and strength training activities are beneficial
- Strive to maintain a healthy weight with a diet that limits saturated fats, concentrated sweets, and alcohol. Individualised nutritional plans can be made in conjunction with a registered dietitian
- Smoking cessation is crucial to reduce the risk of diabetic complications, especially cardiovascular disease.

*Monitoring blood glucose levels*

- Diabetics on insulin therapy are typically advised to check their blood glucose at least three times a day. Blood glucose should be between 4 and 7 mM/L before meals and no more than 7.8mM/L one to two hours after meals

- Home blood glucose monitoring may also help diabetics who are not on insulin therapy achieve their blood sugar goals, but the optimal frequency of monitoring is not known
- Home blood glucose monitoring should be used in conjunction with the haemoglobin A1C test (glycated haemoglobin), which measures the average blood glucose over the past 10–12 weeks. The goal for diabetics is an A1C lower than 7%; however this may need to be higher for some people including children and the elderly. Your doctor or diabetes educator can help you decide on a target that is both appropriate and realistic for your individual circumstances
- In addition to blood glucose monitoring, diabetics should have regular cholesterol and blood pressure checks.

### *Monitoring for diabetes complications*

- May include an electrocardiogram (ECG) or a stress test to check for cardiovascular complications, based on individual risk factors and symptoms

- Yearly blood and urine tests to check kidney function are recommended, and eye exams to evaluate diabetic retinopathy and simple clinical tests for nerve damage (especially in the lower limbs) should also be performed annually
- Monitor for symptoms of hyperglycemia (high blood sugar) which include feeling tired; blurred vision; frequent urination; excessive thirst; and unintentional weight loss
- Monitor for symptoms of hypoglycemia (low blood sugar) which include weakness; trembling or shaking; sweating; light headedness; headache; dizziness; lack of concentration/behaviour change; tearful/crying; irritability; hunger; numbness around the lips and fingers
- Because diabetes increases the risk of foot infections and ulcers, diabetics are advised to check their feet daily for any signs of injury or infection. (The primary care provider should also examine a diabetic client's feet at every visit.) Feet should be carefully washed and dried daily, and socks and supportive footwear are highly recommended. Trimming toenails straight across the tops of the nails can help prevent infections.

## Additional Considerations for Diabetic Women

### *Blood glucose control and the menstrual cycle*

Some diabetic women have decreased insulin sensitivity around the time of menstruation, which may lead to difficulty with glucose control; more intensive monitoring may be needed.

### *Management of yeast infections*

Yeast infections are very common, with about three-quarters of all women having one at least once in their lives. Symptoms include vaginal itching and thick, white vaginal discharge.

Diabetes, especially poorly controlled diabetes, is a risk factor for yeast infections; i.e. high glucose levels promote

yeast attachment and growth, and also interfere with immune responses in the host.

First-line treatment typically involves creams or ointments that are applied directly to the affected areas. Oral treatments are also available but may have interactions with oral medications for diabetes; consultation with a primary care provider is advised. Whether an oral or topical medication is chosen, treatment must include achieving optimal blood glucose control.



## Menopause

Menopause is often called the “change of life” and usually happens in women between 38 and 58 years of age. It is a slow and gradual process that can occur over three to five years while the ovaries slowly stop producing estrogen. This beginning phase is called *peri-menopause*, where periods become less frequent and some other menopausal signs can appear.

Menopause is considered complete when you have not menstruated for 12 months. This marks the end of your fertility and is accompanied by significant hormonal changes.

Prior to the advent of effective anti-HIV treatments, women with HIV reported getting menopause at an earlier age, and having a greater incidence and severity of associated symptoms.

Since treatments, there is less difference in the experience of menopause between HIV and non-HIV infected women, although some studies show the average age of menopause remains younger in women with HIV. It is

unclear whether this difference is due to HIV, or because the other factors associated with earlier menopause (such as drug use or lower body weight) is more common in women with HIV. Further, there was a small proportion of women with HIV in these studies who did not menstruate for over 12 months but still had fully functioning ovaries.

Women with HIV more commonly have irregularities in their menstrual cycle that may be mistaken for menopause. Further, the symptoms of menopause are often hard to distinguish between other symptoms associated with long term HIV infection.

Common symptoms of menopause include:

- hot flushes and night sweats
- crawling or itching sensations under the skin
- vaginal dryness and thinning of the vaginal walls
- reduced libido (sex drive)
- urinary frequency or accidental urination
- tiredness & fatigue
- insomnia (difficulty sleeping)
- mood changes (irritability, forgetfulness, depression).

As menopause completes there are several changes that occur:

- skin changes (becomes more firm and drier)
- cognitive changes (thinking and understanding)
- hair changes (it becomes thinner and more brittle)
- you are at increased risk of bone loss (osteoporosis) and cardiovascular disease.

## What can you do?

### Find common ways to treat or diminish the impact of common symptoms

For example:

- *if you are experiencing sleeping problems:* keeping the windows open, wearing bed clothes made of breathable fabrics, drinking at least eight cups of water a day and keeping water by the bed may be useful
- *if you are suffering from fatigue:* a regular exercise program may make you feel more energetic and regular sleep is important. It may be necessary to prepare food for when you are too tired to cook
- *hot flushes* may be relieved by taking vitamin E. Foods like tofu and soy milk are often suggested because they contain phytoestrogens (chemicals similar to estrogen)

- vitamin B complex is useful for the skin and hair changes that accompany menopause (www.projectaware.org has a comprehensive list of menopausal symptoms and herbal remedies. *However, check all herbal/alternative supplements with your doctor for any interactions with HIV treatments*)
- avoid things which generally increase the risk of menopausal symptoms such as caffeine, spicy foods and excessive alcohol while menopausal.

### If you experience uterine bleeding talk to your doctor

Women with HIV experience abnormal uterine bleeding quite commonly. During and after menopause the risk of urinary tract infections also increases. Many of these are immediately treatable so it is important to see your doctor if you notice either of these symptoms.

### After menopause, take steps to address your increased risk of osteoporosis

If you have not had a hysterectomy and do not have severe liver disease, hormone replacement therapy may be an option for the short term treatment of menopausal symptoms. However, HIV makes the decision about whether to have HRT more complex due its potential for increasing the risk of other conditions common in older women with HIV, so you will need to discuss this with your doctor to tailor a solution to suit your individual needs. Also see the section on bone changes (Page 38) for some other steps you can take to reduce your risk of osteoporosis.

### Living with menopausal symptoms

- Dress lightly and in layers
- Avoid caffeine, alcohol and spicy foods
- Practice slow deep breathing whenever a hot flush starts
- Consider an acupuncturist
- Use relaxation techniques like yoga, Tai Chi or meditation
- Increase your fitness and weight bearing exercises
- Don't smoke
- Adopt a healthy heart diet
- Supplement calcium
- Perform Pelvic floor exercises daily to strengthen the muscles of your vagina and pelvis
- Use water-based lubricants during sex
- Talk to other positive women about their experiences and useful strategies.

## Mental Health

HIV brings changes to our lives and it challenges us, but it's a virus; it is not who we are. There are many things you can do to help manage these challenges. Talking to a counsellor can help or there are organisations that offer courses to help you develop coping skills, including on-line courses.

Depression and anxiety are experienced more commonly by people with HIV, and often symptoms are not obvious. Each time you see your doctor, try talking about how you are feeling. Your doctor can discuss the available support services and treatment options with you if required.

Your local AIDS council or PLHIV organisation can also assist you to find the best support service for your situation.

A good social support network can also be helpful.

### *Dementia and cognitive problems*

HIV crosses the blood brain barrier and infects cells of the brain, usually shortly after infection. As a result long term HIV infection may cause cognitive changes and HIV-associated dementia (HAD).

Prior to the advent of HAART, HAD was very common, but in countries with access to treatments it is now extremely rare unless HIV is diagnosed very late.

Some HIV drugs are more effective at crossing the blood brain barrier than others so it is important to be monitored for any early signs of dementia.

There is a milder cognitive disorder that some people with HIV get that is not necessarily a sign of early dementia.

Dementia and cognitive issues are associated with ageing independently of HIV.

## *What can you do?*

### *Start HIV treatment before problems arise*

If you start treatment soon enough, then HIV-associated dementia is now extremely rare.

### *Monitor for early signs of dementia*

Early manifestations of dementia may include:

- decreased attention or concentration
- reduced speed of information processing
- slowing of psychomotor responses
- some altered higher brain functions that can be tested for.

You will notice things like impaired memory, thinking or judgment, personality changes that interfere with relationships and decreased ability in some social or occupational functions. It is important to realise that these changes may not be a sign of progressive dementia and that if HIV is the cause then swapping treatments may slow down any progress to more advanced dementia.

### *Ask your doctor about getting a baseline neurological test done*

If you are concerned about changes to your cognitive abilities, then getting your current level of cognitive function tested can be a useful tool to assess for any change over the coming years.

*Monitor*

*Decisions*

*Independence*

*Relaxation*

*Support Network*

## Gastrointestinal Health

Normal ageing takes a toll on the gastrointestinal tract. Ageing muscles, including the digestive muscles, contract more slowly, take plenty of time relaxing, and move their contents along at a more leisurely pace; therefore constipation can become a concern as you get older.

In the very earliest phases of HIV infection, HIV attacks the immune defenses of the gut and damages a large proportion of the body's CD4 T-cell reserves.

Diarrhoea is common in people with HIV, either due to infection, as a result of side effects to some drugs used to treat HIV, or from an inappropriate diet.

### *What can you do?*

*Have a good high fibre diet and use vitamin supplements if necessary*

Probably no other organ is impacted more by what you eat than your gut. Examples of good high fibre foods include apples and other fruits such as apricots; peaches; pears; plums; grapes; melons; nectarines; bananas; and grains such as oatmeal; oat bran; white rice; barley and soluble fibre supplements like psyllium (Metamucil) that you dissolve in a glass of water and drink.

*If you have sudden onset of diarrhoea, sudden changes to your bowel movements, any anal bleeding, or unusual itching, get it investigated*

The latest research indicates that there is increasing concern about the rates of anal cancer in people with HIV—particularly in gay men over 50 yrs old—so we need to keep alert for any unusual anal symptoms and talk to your doctor about it.

*If you have persistent diarrhoea there are still things you can do*

You don't have to just 'learn to live with it'. It might be due to the HIV treatments you are on—so maybe talking to your doctor about changing treatments could help. A number of the earlier HIV treatments were significantly associated with diarrhoea, but less of the current drugs are so frequently associated with diarrhoea—but can still be an occasional problem with some current HIV treatments.

Diarrhoea can also be caused by a bad diet—cutting back on fats may reduce diarrhoea. It may also be caused by some food intolerances, so you may want to try reducing dairy products, excess caffeine or sugar, and try eating high fibre foods (see the list above) if nothing else has worked.

For diarrhoea that is caused by protease inhibitors, a higher intake of calcium has been shown to be effective in reducing or eliminating it. If all else fails then there are anti-diarrhoea medicines that your doctor may recommend; but they do have to know it's a problem for you before they can recommend anything, so don't just 'live with it'—tell your doctor about it.

## Dental Health

Having HIV and the side effects of some HIV medications can both affect your dental health, including reducing the amount of saliva in your mouth which can lead to tooth decay.

There is also an increased likelihood of gum and mouth disorders, such as oral thrush and badly bleeding gums, particularly during the early stages of HIV.

Emotional factors such as stress and anxiety, nutritional factors, as well as some HIV medications can cause a higher likelihood of teeth clenching and grinding. This can cause wearing of the teeth and make teeth sore and sensitive.

## What can you do?

### *Regular visits to the dentist are recommended for people with HIV*

It is important to see your dentist every six to twelve months to monitor these and other conditions so they can discuss prevention and treatment options with you.

You can speak to your AIDS council or PLHIV organisation about dental schemes that may be available to you.

As with all healthcare workers, it's a good idea to let dentists know if you have any serious medical conditions or are taking any medications. This will help them ensure that you receive the most appropriate treatment. It is both wrong and illegal for dentists or any other health professional to discriminate against you because of your health status, race, or sexuality. General hygiene precautions are enough to prevent the transmission of HIV during dental treatment.

## Disclosure

People living with HIV who seek treatment for an age-related illness, which is not related to their HIV, can sometimes feel short changed because their sexuality and positive status may become a priority in some health care settings.

If you are not happy with the quality of health care you receive, you have the right to complain. The contacts section of this booklet has a list of the Health Service Complaints Commissions in each state and territory.

Some people can't disclose to their families for fear of losing the only support they may have or from some being overly supportive and too protective.

Although you are not obliged to tell anyone your status, the law may require you to tell people under certain circumstances. In some states, you are legally required to tell any sexual partner, even if you intend to have safe sex. These laws vary from state to state so it's best to check with your local Legal Aid Centre or AIDS council to see how the laws in your particular state might impact on your decision, especially given that some cases of non-disclosure have ended up in court.

## What can you do?

### *Tips for disclosing your HIV status:*

- you can never take back disclosure, or control how people will react. If you think the person will have a bad reaction, leave it until you feel more confident that you can handle it, or don't tell them
- be careful about disclosing to people who might gossip
- it might be helpful to rehearse what you want to tell people beforehand
- remind the person to keep it confidential, but accept that they will need to talk to others about it. Ask them to be careful who they tell or suggest other people who they could talk to for support
- positive people are often put in the position of being an educator. This can be onerous, but people who do not know much about HIV may expect you to inform them
- it can be hard to tell the children in our lives that we have HIV. Explain things in simple ways so that it's easy for them to understand.

# Managing Social Change

Community

Energy

Routine

Networking

Desire

Socialise

Goals

*In this chapter people with HIV discuss the personal and social implications of ageing, and discuss their strategies for coping with change.*

Each section includes practical suggestions which may help meet the needs of people living longer with HIV. Looking beyond HIV to a fuller life and being able to see the person not just the disease is an important mantra for many individuals to achieve this personal goal. This may be especially so for people who were diagnosed in the 1980s—whom were often given a death sentence back then and may not have prepared themselves to be alive 20 years later.

## Sex

A commonly held view about older people is that they are either asexual or exclusively heterosexual. However, research has shown that older people are sexual and that sexual expression is important for health and wellbeing and that some older people are gay, lesbian, bisexual, transgender and intersex or may be a sex worker.

For many people as they get older sex can lessen in importance compared with when they were younger. For others it is still an essential part of their life. You may not be defined by your sexuality or your HIV status, but whatever your path is, this part of your life is important. This chapter covers some ways for you to achieve your sexual desires.

Negotiating sex can always be a challenge; however we often gain experience and confidence as we age. No longer fumbling teenagers, we may have a better understanding of intimacy and sexuality. Whether looking for an intimate connection or just sex, life experience may assist us in meeting our needs.

Attitude

*“These days I look for something more, a connection and intimacy—not just sex—and someone who shares my values.”*

*“As I’ve gotten older there’s less of an imperative to have sex. I’m less driven. There’s been a gradual change in my sex drive and I’ve adjusted to that.”*

Confidence

Pick-up

Intimacy

*“If I’m feeling low, I can run myself down thinking I’m too old for the bars, but another day, when I’m feeling good I don’t even think about it, can have a great time and sometimes pick-up. It’s not always the bars that exclude me—sometimes it’s my own pessimistic attitude”.*

## What can you do?

Get out and about; explore experience and enjoy.

- Go by yourself if you feel comfortable, or ask a friend along for company.
- Aim for fun and see what happens.
- You never know who you might meet!

Use the world wide web as an opportunity to socialise online or meet socially

There are websites that cater specifically to older gay men and their admirers, people over 50, volunteers and all sorts of social networking sites. Most are based in the USA, but all these listed below include extensive content and/or members in Australia:

- **CAFFMOS “for mature gay men and gay daddies”** Extensive dating for mature gay men and their admirers, worldwide. Photos, pen-pals, chat-rooms, and links to other senior sites. Includes a substantial number of members in Australia. [www.caffmoscommunity.com](http://www.caffmoscommunity.com)
- **Club Silver** Gay personals site dedicated to mature gay and bisexual men, and their admirers. [www.clubsilver.org](http://www.clubsilver.org)
- **Fridae** A social networking site for gay/bi men of all ages. Fridae labels itself as ‘empowering Asian men’. Whilst it is not exclusively for older guys it attracts a large older group. [www.fridae.com](http://www.fridae.com)
- **Elder TG (transgender)** A USA support group for transgender individuals aged 50-plus and for their partners, friends, family and allies. [www.forge-forward.org](http://www.forge-forward.org)
- **Mature Aged Gays (MAG)** A peer support, social and educational group targeting mature age men 40-plus who have sex with men, regardless of how they choose to identify themselves. <http://www.magnsw.org/>

- **Prime Timers (USA)** “The purpose of our organization is to provide mature gay and bisexual men, and their admirers, with opportunities to come together in a supportive atmosphere to enjoy social, educational, and recreational activities.” [www.primetimersww.org](http://www.primetimersww.org)
- **‘Planning for later life as a lesbian, gay man, bisexual or transgender person’** Information Sheet from ‘Age Concern’ in the UK: information for older lesbians, gay men and bisexuals planning for later life. [www.ageconcern.org.uk](http://www.ageconcern.org.uk)
- **50plus Online Magazine (USA)** A general readership web magazine for people ages 50-plus. The relationships section includes articles on gay and lesbian ageing. [www.50plusmag.com](http://www.50plusmag.com)
- **The Centre for Volunteering** Volunteering is as diverse as the huge number of Australians currently involved. Visit their site to find out about hundreds of volunteering opportunities. [www.volunteering.com.au](http://www.volunteering.com.au)
- **Chatmag.com** “Comprehensive List of AIDS/HIV and Poz Chat Rooms on IRC and The Internet”. They’re not all heterosexually-focused, but you’ll find what you’re looking for. [www.chatmag.com/topics/health/aids.html](http://www.chatmag.com/topics/health/aids.html)

- **PositiveSingles.com** Dating site for folks with all manner of sexually-transmitted infections, including herpes as well as HIV. [www.positivesingles.com/](http://www.positivesingles.com/)
- **Poz.com chat** A chatroom for HIV-positive heterosexuals. <http://hiv-aids.poz.ca/chat/hetero/>
- **PozMatch.com** Personals ads from the Living Positive Community. Global. All-inclusive. [www.poz-match.com/index.php?page=index](http://www.poz-match.com/index.php?page=index)
- **Touching Base Inc.** Developed out of the need to assist people with disabilities and sex workers to connect with each other, focusing on access, discrimination, human rights and legal issues and the attitudinal barriers that these two marginalised communities can face. General Enquiries: [info@touchingbase.org](mailto:info@touchingbase.org)
- **PozVibrations.com** A fun & secure community environment to help you find a match regardless of sexual orientation, race, gender or religion. HIV+ Dating Australia. [www.pozvibrations.com](http://www.pozvibrations.com)

## *Have safe sex*

Use condoms with a water-based lubricant to avoid passing on HIV and protect you and your partners from some other STIs. There is a very low risk of passing on HIV through oral sex, but using a condom or dental dams will also protect you and your partners from some other STIs.

## *Remember PEP is available*

Accidents can happen. If you think you may have exposed another person to HIV, find out where they can get PEP treatment to prevent HIV infection taking hold.

PEP (post-exposure prophylaxis) must be started within 72 hours of exposure, but within a few hours is best.

For more information about PEP and where it is available, call your nearest major hospital, call your AIDS Council, or go to [www.getpep.info](http://www.getpep.info)

## *Viral load & infectiousness*

HIV is still present, even if you have an undetectable viral load. The virus remains in very small amounts, which are unable to be accurately measured by current blood tests.

It is possible to have a low or undetectable blood viral load, but higher levels of HIV in other body fluids such as semen, vaginal fluids and the fluid lining of the rectum and anus. This would increase the chance of passing on HIV to your partners.

While research suggests an undetectable blood viral load reduces the risk of passing on HIV, it has not yet been proven to completely eliminate the risk. Having an undetectable viral load result at your last test is not a substitute for safe sex.

## *Secondary infections*

Having another infection when you are HIV positive places further stress on your immune system as well as makes the other infection more serious.

If you have a sexually transmissible infection (STI) as well as HIV, then both the STI and HIV can be easier to pass on to your partners. Some STIs can also increase your viral load and decrease your CD4 count. Get regular sexual health check-ups (blood and urine tests as well as throat, vaginal and anal swabs). Many STIs do not have symptoms.

There is an increased risk of hepatitis B transmission through anal sex.

If you and your partner are both HIV positive and do not use condoms, there is a possible risk of being exposed to a different strain of HIV. Being infected with a different strain (reinfection or superinfection) can limit your treatment options. Speak to your doctor or AIDS council or PLHIV organisation for more information.

*Information*

*Prevention*

*Undetectable*



## Your Home

*“Living alone has its pros and cons, but it’s not a problem for me. As you get older you can get more set in your ways and more difficult to live with. You can be more selfish. I’ve got used to my own company and there are advantages to being able to please myself... I enjoy living alone”*

*“If there was someone that I really connected with I might consider sharing my life with them and live together”.*

Although living alone can be challenging for some, others enjoy the freedom to do as they please. For those who choose not to be alone, sharing with a partner or friend can be a supportive and cost-effective option. Taking in lodgers can also be an option for those with a spare room. Advantages in both cases include shared living expenses, enlarged friendship networks and options for support and entertainment.

### *What can you do?*

*Pets are wonderful support, providing companionship and entertainment.*

For dog owners, routine daily walks can improve health, reduce social isolation and allow opportunity for social interaction with other pet owners.

*Homes and gardens - large or small a garden provides an opportunity for creativity, exercise, and interaction with other gardeners.*

For those who enjoy establishing and tending a garden, finding a property that has a courtyard, balcony or backyard could be a priority.

Enjoy your home by caring for it. Make it a refuge and an enjoyable haven. Your home can be a testament to your life. The more you care for your home, the more it will care for you, and the more you care about your home, the more you will feel able to share it with others.

*Call a friend and invite them over for a visit.*

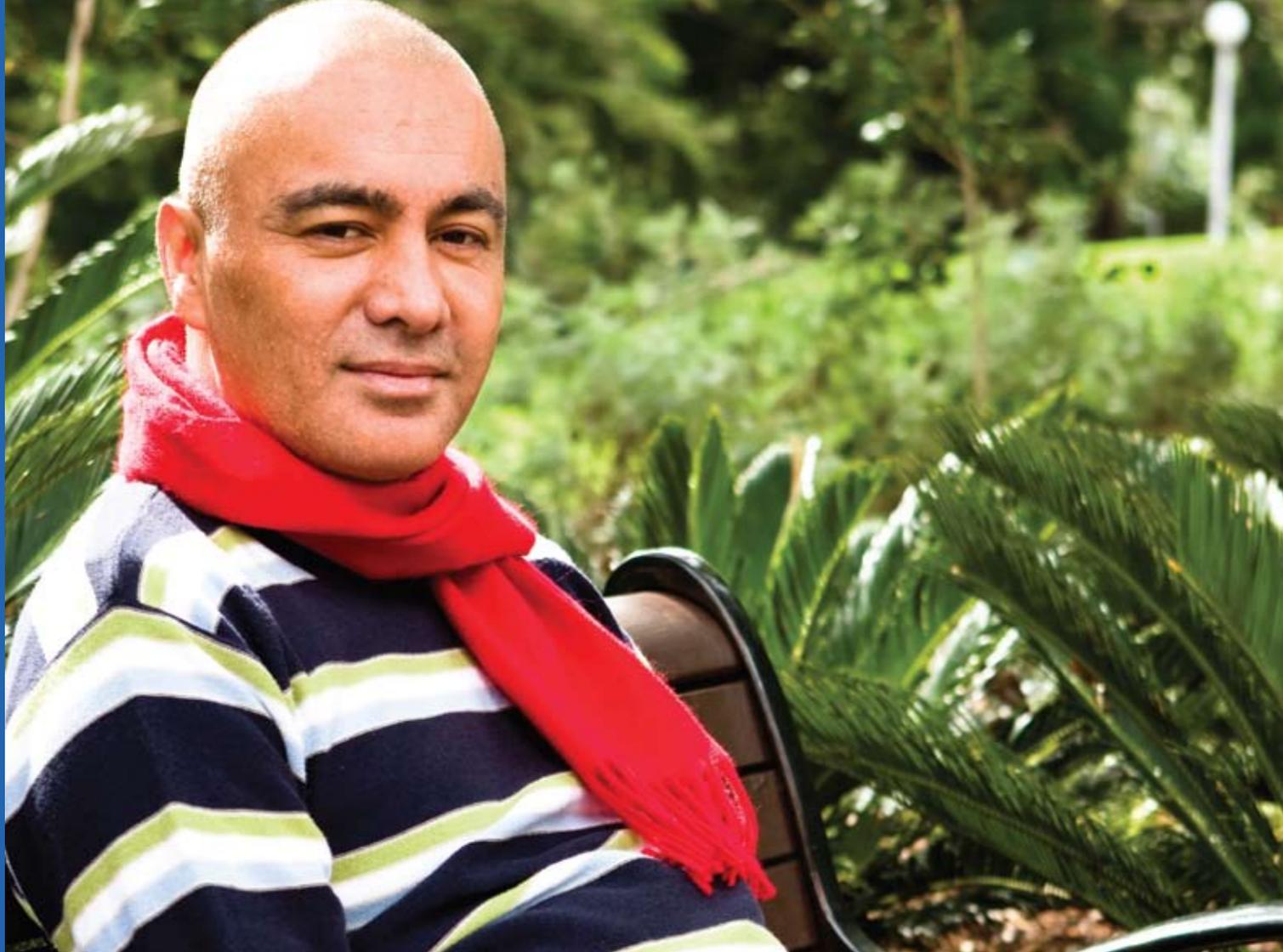
Try using a public holiday, a sports event, or a birthday as a reason to invite people around. The more you invite people, the more likely you are to be invited to others' events.

Social interaction has a momentum of its own; the more sociable things you choose to do, the more social things will happen to you.

## Being Alone, but not Lonely

Ageing brings many changes to the type of company you keep. The end of work, loss of friends, periods of illness, reduced energy, and change of address or living arrangements can all lead to a decline in social contact. It's important to recognise that while these factors may influence our lives, there are other options.

Many people have told us they are actively working to reduce loneliness and isolation in their lives. They stressed the importance of maintaining contact with other people, particularly those who they have a special connection with and particularly those also living with HIV who they can share their experiences with.



## Friendship

Human company and social networks are life giving because of the way they provide support, information, pleasure and connection. Getting out-and-about and interacting with others helps maintain social skills, keeps you mentally healthy and active. Relationships with friends and lovers provide companionship, support and someone to share life's ups and downs with.

If you find your social life has shrunk it's time to take steps to improve your situation. Looking for new ways to keep busy and develop new friendships can significantly improve your ability to achieve happiness and social fulfillment.

## Families

Family can be a difficult balancing act. The acceptance, understanding and support they can offer can often be dependent on many factors including their knowledge and understanding of HIV. Getting support, acceptance and understanding from family members can take time and effort, but might be worth it in the end.

*“You need to surround yourself with people you have something in common with. It’s important to keep in contact with people, especially younger people... Work was my main contact with others and when that ended I really missed the social contact. But volunteering has been a joy. It kept me busy with other people and makes me feel like I’m still useful”.*

## Pets

The companionship and affection of pets can also be a wonderful support. They can become a pivotal part of our lives, providing companionship, a reason to get up in the morning and boundless affection and devotion.

### *What can you do?*

#### *Social support*

Support from family, friends and other people in the same boat can really help. Build a support network and stay in touch.

AIDS councils or PLHIV organisations offer a range of opportunities for HIV-positive people to build friendship networks, meet people and share information to enhance your health and well-being, including workshops and social events. Contact them for more information on these and to find out where you can meet other people with HIV.

Listed below are a range of suggestions and strategies that have been used by people living longer with HIV:

- stay close with your friends and make time to get together. Invite them over for a meal. Watch a movie together or go for a walk. Maybe organise a holiday or trip together. Friendships need attention or they can drift away
- contact an old friend or acquaintance and re-connect
- share stories with other positive people
- find meaningful volunteer work
- do something special with a friend/your partner/lover or someone special. They can be a great source of comfort and happiness
- meet new people
- do something special with a friend or someone special.

## Finances and Planning for the Future

HIV treatments can be expensive and some HIV-positive people have trouble paying for their treatments. Some people are finding recent changes to social security requirements challenging. If you are experiencing financial difficulties for these or any other reasons, there are organisations that can help.

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

You can contact legal assistance organisations such as the HIV/AIDS Legal Centre (HALC), Legal Aid organisations, or your AIDS council or PLHIV organisation for help in contacting organisations that can assist you in financial and legal areas.

## Home Help and Supported Accommodations

*“For me it’s about what we need in terms of a sensitive living environment... and what we are going to do about it”*

When we live on to older age, we may find we are no longer be able to care for ourselves and we may need to think about options for getting help to manage at home or even consider a retirement home or supported accommodation. In addition, some people living with HIV may not have family or friends who are able to be carers for example, sometimes gay men may have disconnected with family and may not have children, this may make reduced options for care as they age.

Some gay men with HIV may prefer to have aged care support from providers who are particularly sensitive to gay issues, and some have indicated that they would prefer aged care facilities solely for members of the GLBT community.

In the past, the gay and lesbian community has responded to community needs and set up its own organisations and support services. People have suggested this may again happen with community organisations like ACON and Gay and Lesbian Health Victoria advocating for appropriate care and support services with government and the private sector.

Depending on financial circumstances, health and independence you may need to consider Home and Community Care (HACC), or a Community Aged Care Package (CACP) to help you stay living at home longer.

HACC services provide a comprehensive, coordinated and integrated range of basic maintenance and support services for frail aged people, people with a disability and their carers including:

- community nursing
- personal care
- meals
- home help
- home modification and maintenance
- transport
- community based respite care.

The program also supports these people to have a higher level of independence within their community. It enhances their quality of life and allows older Australians the option of remaining at home rather than moving to an aged care facility.

## Aged Care Assessment Teams (ACATs)

ACATs help older people and their carers work out what kind of care will best meet their needs when they are no longer able to manage at home without assistance. ACATs provide information on suitable care options and can help arrange access or referral to appropriate residential or community care services such as Home and Community Care (HACC). An ACAT assessment and approval is required before people can access residential aged care, Community Aged Care Packages (CACPs) or Extended Aged Care at Home (EACH) Packages.

CACPs are individually planned and coordinated packages of care tailored to help older Australians remain living in their own homes. They are funded by the Australian Government to provide for the complex care needs of older people and include:

- personal care
- social support

- transport to appointments
- home help
- meal preparation
- gardening.

If you, your family or your representatives are not happy with the service provided under a Community Aged Care Package, you have the right to complain. The Australian Government has put arrangements in place for people to do this. If talking to the service provider cannot solve the problem, the **Aged Care Complaints Investigation Scheme** is available. This is a free service which is overseen by the Aged Care Commissioner.

The Aged Care Complaints Investigation Scheme can be contacted on **1800 550 552**.

Recipients of a CACP, their family and their representatives are also entitled to access advocacy services. Advocacy services help people find out what they are entitled to.

For information on advocacy services, please contact the Aged and Community Care Information Line on **1800 500 853**.

## Extended Aged Care at Home (EACH)

EACH packages are individually planned and coordinated packages of care, tailored to help frail older Australians to remain living at home. They are funded by the Australian Government to provide for the complex care needs of older people.

EACH packages are very flexible and designed to help with individual care needs. Generally a person who requires high level care could be eligible for an EACH package, and the types of services that may be provided as part of an EACH include:

- registered nursing care
- care by an allied health professional such as a physiotherapist, podiatrist or other type of allied health care

- personal care
- transport to appointments
- social support
- home help
- assistance with oxygen and/or enteral feeding.

To receive an EACH package you must be assessed by an Aged Care Assessment Team (ACAT), as requiring high level care. ACAT assessments are free of charge. If EACH packages are available in your area, you have been assessed as requiring high level care, and expressed a preference to be cared for at home, then you may be offered an EACH package of care.

Information on ACATs is available from doctors, hospitals and community centres, or the Aged and Community Care Information Line on 1800 500 853, or Commonwealth Respite and Carelink Centres on 1800 052 222\* (\*mobile calls are charged at applicable rates).

*Professional*

*Preference*

## Extended Aged Care at Home Dementia (EACH D)

EACH D packages are aimed at those at the highest end of the community care continuum. The EACH D packages will assist people with dementia who experience difficulties in their daily life because of behavioural and psychological symptoms associated with their dementia.

EACH D packages are very flexible and designed to help with individual care needs. The packages provide the same full range of services that EACH packages provide including:

- registered nursing care
- care by an allied health professional such as a physiotherapist, podiatrist or other type of allied health care

- personal care
- transport to appointments
- social support
- home help
- assistance with oxygen and/or enteral feeding.

To receive an EACH D package, you must be assessed by an Aged Care Assessment Team (ACAT), as requiring high level care and:

- experiencing behaviours of concern and psychological symptoms associated with dementia that is significantly impacting upon your ability to live independently in the community require a high level of residential care
- prefer to receive EACH D package
- are able to live at home with the support of an EACH D package.

*Health Care*

*Community*

## Residential Care Services

Residential care services provide accommodation and support for people who can no longer live at home.

To enter a residential care service, you will need to be assessed by an Aged Care Assessment Team. Two levels of residential care are provided in Australia. These are low level (hostel) services, and high level (nursing home) services.

- Respite care services are also available in residential care facilities
- Residents may be asked to contribute to the cost of residential care
- All residential care services are required to maintain standards. They must provide high quality care to every resident, and make sure they have qualified staff to meet residents' needs
- Your rights in residential care are the same as those of any other Australian.

## Making Decisions for the Future

Making decisions about the choices for our end of life phase is never easy, but it is important. Advance Care Planning (ACP), is a way in which people can talk with their family and health professionals about the choices for care at the end of their life.

Newer and more sophisticated health technology means that people can be kept alive for longer by mechanical and artificial methods. This also means that people should be thinking about what this might mean for them if they were placed in that situation.

Advance Care Planning addresses fears and concerns through a process which assists competent people to make decisions about their healthcare for a possible future time when they may no longer be competent.

There are two types of mechanisms for this advanced care planning:

### 1. Financial

#### **Enduring power of attorney (financial).**

An enduring power of attorney (financial) is a legal document where you (the donor) give someone (the attorney) the power to make financial and legal decisions for you—like managing your banking, your property or paying bills. Enduring means the power continues (endures) even when you are unable to make these types of decisions for yourself.

#### **How does it work?**

You complete, sign and have witnessed an enduring power of attorney (financial) form, giving power of attorney to someone you choose.

On the form you can specify the powers you are giving and when they begin, and place conditions on the decisions your attorney can make.

Your attorney agrees by signing the acceptance section of the form.

Your attorney's decisions have the same legal force as if you had made them yourself.



You can appoint an attorney if you are over 18 years of age and have the capacity to make the appointment.

An enduring power of attorney (financial) can make any financial and legal decisions that you can. On the form you can limit or place conditions upon how you want your attorney(s) to carry out their responsibilities. An enduring power of attorney (financial) cannot be used to make medical treatment or lifestyle decisions.

**Choosing your attorney.**

An attorney must be over 18 years of age and have the capacity to be your attorney. You can appoint any person or organisation, as long as they agree to take on the role and must accept the appointment in writing. They should be someone that you trust to manage your affairs, and look after your best interests.

You may choose to appoint more than one attorney. Their power can be exercised:

- jointly (they must make decisions together)
- jointly and severally (they can make decisions together or independently)
- severally (they can make decisions independently of one another)
- alternatively (the alternative attorney can only make decisions when the first attorney is unable to).

*2. Personal & lifestyle decisions*

**Enduring power of guardianship.**

This allows a competent person over 18 yrs old to appoint and Enduring Guardian (EG) to make personal and lifestyle decisions—like where you live and the health care you receive, on their behalf incase they loose the capacity to make their own decisions.

The Enduring Guardian must be at least 18 yrs old, must agree to the appointment as EG and understand the principal wishes of the person who has appointed them (the donor) and be willing to carry them out. The appointment must be in writing and signed by the principal EG and a solicitor, barrister or clerk of the courts—these signatures can be witnessed separately.

If you give your guardian the power to make healthcare decisions, they can agree to medical treatment but cannot refuse medical treatment. If you have also appointed someone with enduring power of attorney (medical treatment)—they will take precedence over your guardian for all medical treatment decisions.

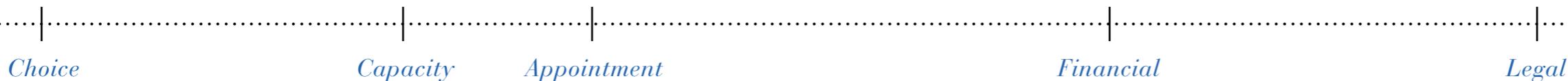
A guardian cannot agree (consent) to the following medical procedures:

- those likely to lead to infertility
- termination of a pregnancy
- removal of tissue for transplant.

The EG is usually a relative or friend, but cannot be at the time of appointment as EG:

- the person who provides medical treatment or professional care
- someone who provides accommodation services or support services for daily living on a professional basis
- is a relative of one of the above.

There can be more than one EG appointed in case the original EG dies or becomes incapacitated. If more than one is appointed, the principal EG needs to state how decisions will be made (jointly or separately).



**Advanced Health Care Directive.**

This is a written document allowing a person to make their wishes known for their future healthcare. It extends the current right of a competent person to refuse treatment to a future time when they may not be competent and it only comes into effect when the person making it actually loses their decision making capacity. It is NOT a form of euthanasia because it only allows actions which a person could legally consent to themselves; if they are able to speak or communicate in some way.

The benefits of an Advanced Health Care Directive are:

- it gives control back to the person by ensuring their wishes are known
- it assists the healthcare provider with decision making
- it relieves loved ones stress at an often traumatic time
- it allows the person to live well now by taking away fear of the end stage of their life sometime in the future.

Where should it be kept?

- a copy in the GP and any specialists' files
- a copy with the Enduring Guardian (EG)
- a copy accessible at home
- on admission to hospital or residential aged care facility (to be placed in the patients record to be available for subsequent admissions and to guide care plans
- in an accessible place (like on the fridge) in case ambulance officers are called.

### *Enduring power of attorney (medical)*

An enduring power of attorney (medical treatment) is a legal document where you (the donor) appoint someone (the agent) to make medical treatment decisions for you—like agreeing to medication or surgery. Enduring means it continues (endures) when you are unable to make these types of decisions for yourself.

**How does it work?**

- You complete, sign and have witnessed an enduring power of attorney (medical treatment) form—giving power of attorney to someone you choose
- Their power begins when you are unable to make decisions
- Your agent's decisions have the same legal force as if you had made them yourself
- You must be over 18 yrs old and have the capacity to make the appointment
- An enduring power of attorney (medical treatment) is easy to make. It does not have to be prepared by a lawyer
- Witnesses to the signing of the form have to be assured that you, as donor, know what you are doing (have capacity) in making the power of attorney
- If there is any question about your capacity, an independent medical assessment should be obtained. It would be wise to seek legal advice

**What type of decisions can an agent make?**

An agent can agree to or refuse medical treatment including your involvement in medical research. They can only refuse medical treatment if:

- the treatment would cause you unreasonable distress, or
- the agent reasonably believes that you would consider the treatment unwarranted.

**An agent's decision takes precedence over those of an enduring guardian you may have appointed who has healthcare powers.**

An enduring power of attorney (medical treatment) cannot be used to make financial, legal or guardianship decisions.

**Choosing your agent.**

An agent must be over 18 years of age and have the capacity to be your agent. You can appoint any person you choose, as long as they agree to take on the role. They should be someone that you trust to respect and carry out your wishes. You can also choose to appoint a

second person (an alternate agent). They can only make decisions on your behalf when the agent is unable to.

Please note: There may be variations to the law in different states and territories in Australia, so it is advisable to contact your state office of the Public Advocate, where 'Power of Attorney' forms can also be downloaded from their websites.

## Taking Control

*“Everyone fears losing control of their independence, health and self esteem”.*

Many people told us that they believed taking responsibility for their physical and emotional health had been the single most important factor that enabled them to survive HIV.

*“For many of us who were diagnosed with HIV before combination therapy, we’ve been through enormous change as well as difficult times. We’ve faced our own death and the death of lovers and friends. We’ve learned to roll with the punches... and that’s helped to make us strong and resilient.”*

Diagnosis

Control

For people diagnosed before effective antiretroviral treatments arrived in 1996, the experience of HIV was very different. Coming to terms with a physical, emotional and social reality that was constantly shifting into unfamiliar territory was immensely challenging. People had to face their own mortality as they lived with a potentially fatal disease and come to terms with an uncertain future. Dealing with the loss of lovers and friends was a very different experience from today when hardly anyone dies of AIDS and where HIV treatments have resulted in HIV being a manageable chronic condition.

*“I’ve noticed a difference in attitude between people who were diagnosed before treatments became available*

Experience

*in 1996. It’s a different experience of living with HIV, and that experience affects a whole range of issues.”*

Those who lived to tell the tales have already learned strategies to manage during periods of ill health and emotional turmoil.

*“I control what happens to me. I’ve now got more control in my life than ever before. I refuse to be a victim”.*

Mentality

# A Checklist *for* Healthy Ageing *with* HIV

Optimise

Clarity

Treatment

Diagnoses

Discussion

Assessment

Balance

Improve

*This chapter provides a list/checklist of the sorts of things you might consider when planning for a longer and healthier life with HIV.*

*Define your health goals now—your aim is optimum health!*

You may like to go through this list and tick off the things you feel you have under control and circle the ones you feel you may need to change now, or might have to plan ahead for. You might choose to discuss your health with your GP or HIV doctor if you are unclear, or have any questions.

- Find an experienced and communicative doctor, whom with you feel comfortable.
- Know about HIV treatments and when you should start taking them.
- Follow the recommended dosing instructions if you are taking ARV treatments.
- Avoid treatment breaks.
- See your HIV doctor every 3 months to monitor your viral load and CD4 count.
- If side effects are a problem, don't just put up with them; talk to your doctor about changing treatments, but don't stop treatments.
- Regularly monitor your overall health, this includes:
  - blood pressure, blood lipids, blood glucose, liver & kidney function tests, and a bone mineral density test, including a DEXA scan if applicable
  - routine annual cardiological assessment—ECG, stress tests or cardiac ultrasound if relevant.
- Understand the significance of the risk of cardiovascular disease (CVD). Initiate a discussion about your cardio health and/or risk with your doctor.
- Take steps to change risk factors of CVD, diabetes, bone density loss, liver and kidney disease:
  - stop smoking—the first step is to set a date
  - reduce alcohol consumption
  - maintain a healthy weight
  - eat a balanced diet—reduce saturated fats, salts and sugars, increase fibre intake and include calcium in your diet
  - undertake regular physical activity
  - drink 6—8 glasses of water a day.
- Prevention is better than a cure, so consider lifestyle changes now. If you have been diagnosed with any of the following, take active steps to improve your health:

- low bone mineral density—talk to your doctor about prescribed medications for osteoporosis, calcium and vitamin D supplements, and get plenty of sunshine
- elevated lipids—discuss with your doctor the pro's and con's of diet and exercise modification and/or taking lipid lowering agents
- high Blood Pressure—discuss with your doctor diet and exercise modifications vs. anti-hypertensive medications.
- If you are diagnosed with pre-diabetes or insulin resistance—act NOW. See a dietician and prevent the onset of diabetes.
- Avoid urinary tract infections (UTIs)—avoid constipation, get vaginal infections treated quickly and if you get a UTI treat it quickly.
- Monitor for early signs of dementia—if you are worried ask your doctor for a baseline neurological assessment. Consider starting ARVs before problems arise.
- Avoid the risk of cancer—any sudden onset of diarrhoea, anal or vaginal bleeding should be investigated. Check your breasts and testicles monthly for any unusual lumps or changes in appearance.
- Get tested for hepatitis A, B & C—if you're negative then consider hepatitis A & B vaccinations and get appropriate treatment if you have hepatitis C.
- Get vaccinated for pneumonia and flu each year.
- See your dentist every six to twelve months.
- Know about therapeutic drug interactions and inform your doctor about all the drugs you are taking.
- Know about recreational drug interactions.
- Manage social change in your life—get out, explore and enjoy life, make the effort to stay in touch with friends.
- Take control of your health and plan ahead.

# Support *Services* Contact *Details*

*Collaborate*

*Alliance*

*Place*

## *AIDS Councils*

AUSTRALIAN CAPITAL TERRITORY  
**AIDS Action Council of the ACT**  
Tel 02 6257 2855  
www.aidsaction.org.au

NEW SOUTH WALES  
**ACON**  
Tel 02 9206 2000  
TTY 02 9283 2088  
Freecall 1800 063 060  
www.acon.org.au  
  
Hunter/Mid-North coast 02 4927 6808  
Illawarra 02 4226 1163  
Northern Rivers 02 6622 1555

*Assistance*

NORTHERN TERRITORY  
**Northern Territory AIDS and  
Hepatitis Council**  
Darwin 08 8944 7777  
Freecall 1800 880 899  
Alice Springs 08 8953 3172  
E: info@ntahc.org.au www.ntahc.org.au

WESTERN AUSTRALIA  
**Western Australian AIDS Council**  
08 9482 0000  
www.waaid.com

QUEENSLAND  
**Queensland Association for  
Healthy Communities**  
Brisbane and South East Qld 07 3017 1777  
Freecall (outside Brisbane) 1800 177 434  
Men's Sexual Health Line Freecall 1800 155 141  
Cairns 07 4041 5451  
Sunshine Coast 07 5451 1118  
www.qahc.org.au

*Action*

*Connect*

SOUTH AUSTRALIA

**AIDS Council of South Australia**

Tel 08 8334 1611

Freecall 1800 888 559 TTY: 08 8362 0306

Man2Man Information line:

08 8334 1617 or 1800 671 582 (outside Adelaide)

[www.acsa.org.au](http://www.acsa.org.au)

E: [information@acsa.org.au](mailto:information@acsa.org.au)

[www.acsa.org.au](http://www.acsa.org.au)

TASMANIA

**Tasmanian Council on AIDS, Hepatitis and Related Diseases (TasCAHRD)**

Tel 03 6234 1242

Freecall 1800 005 900

[www.tascahrd.org.au](http://www.tascahrd.org.au)

VICTORIA

**Victorian AIDS Council / Gay Men's Health Centre**

Tel 03 9865 6700

Freecall 1800 134 840

TTY 03 9827 3733

[www.vicaids.asn.au](http://www.vicaids.asn.au)

*PLHIV Groups*

AUSTRALIAN CAPITAL TERRITORY

**PLWHA ACT**

Tel 02 6257 4985

[www.aidsaction.org.au/plwaha](http://www.aidsaction.org.au/plwaha)

NEW SOUTH WALES

**Positive Life NSW**

Tel 02 9361 6011

Freecall 1800 245 677

[www.positivelife.org.au](http://www.positivelife.org.au)

**Positive Living Centre (PLC)**

Tel: (02) 9699 8756

Email: [plc@acon.org.au](mailto:plc@acon.org.au)

**The Luncheon Club**

The Gordon Ibbett Activity Centre

77 Kellick St Waterloo

Tel: (02) 9206 2000 or 0400 446 712

Email: [lunch@luncheonclub.net.au](mailto:lunch@luncheonclub.net.au)

**Heterosexual HIV/AIDS Service (Pozhet)**

Freecall: 1800 812 404

02 9395 0444

Email: [pozhet@pozhet.org.au](mailto:pozhet@pozhet.org.au)

[www.pozhet.org.au](http://www.pozhet.org.au)

NORTHERN TERRITORY

**PLWHA NT**

Tel 08 8944 7777

Free Call 1800 880 899

E: [info@ntahc.org.au](mailto:info@ntahc.org.au)

[www.ntahc.org.au](http://www.ntahc.org.au)

QUEENSLAND

**Queensland Positive People (QPP)**

Statewide Resource Centre

Brisbane 07 3013 5555

Freecall 1800 636 241

[www.qpp.net.au](http://www.qpp.net.au)

**Spiritus Positive Directions**

Tel 07 3900 8000 or 1800 422 313 (outside Brisbane)

E: [pdinfo@spiritus.org.au](mailto:pdinfo@spiritus.org.au)

[www.positivedirections.org.au](http://www.positivedirections.org.au)

SOUTH AUSTRALIA

**PLWHA SA**

Positive Living Centre

Tel 08 8293 3700

[www.hivsa.org.au](http://www.hivsa.org.au)

**Mosaic Services (Relationships Australia South Australia)**

Counselling and case management support for people living with HIV and Hepatitis C

08 8223 4566

Free call for country callers: 1800 182 325

[www.rasa.org.au](http://www.rasa.org.au)

TASMANIA

**Tasmanian Council on AIDS, Hepatitis and Related Diseases (TasCaHRD)**

Tel 03 6234 1242

[www.tascahrd.org.au](http://www.tascahrd.org.au)

VICTORIA

**PLWHA Victoria**

Tel 03 9865 6772

E: [info@plwhavictoria.org.au](mailto:info@plwhavictoria.org.au)

[www.plwhavictoria.org.au](http://www.plwhavictoria.org.au)

**Positive Women Victoria**

03 9276 6918

[www.positivewomen.org.au](http://www.positivewomen.org.au)

**Straight Arrows**

Freecall 1800 027 697 or 03 9276 3792

[www.straightarrows.org.au](http://www.straightarrows.org.au)

WESTERN AUSTRALIA

**HAPAN**

Tel 08 9482 0000

[hapan@waaid.com](mailto:hapan@waaid.com)

*Services for Current and Past  
Injecting Drug Users*

NATIONAL

**Australian Injecting and Illicit Drug  
Users' League (AIVL)**

(02) 6279 1600

[www.aivl.org.au](http://www.aivl.org.au)

AUSTRALIAN CAPITAL TERRITORY

**Canberra Alliance for Harm Minimisation  
and Advocacy (CAHMA)**

Tel 02 6279 1670

NEW SOUTH WALES

**New South Wales Users &  
AIDS Association (NUAA)**

Tel 02 8354 7300

Freecall 1800 644 413

[www.nuaa.org.au](http://www.nuaa.org.au)

QUEENSLAND

**Queensland Injectors Health Network (QUIHN)**

Brisbane 07 3620 8111

Freecall 1800 172 076 (Outside Brisbane)

[www.quihn.org.au](http://www.quihn.org.au)

Gold Coast 07 5520 7900

Sunshine Coast 07 5443 9576

Cairns 07 4051 4742

Rockhampton 07 4923 7443

SOUTH AUSTRALIA

**South Australian Voice in  
IV Education (SAVIVE)**

Tel 08 8334 1699

[www.acsa.org.au/SAVIVEmail.html](http://www.acsa.org.au/SAVIVEmail.html)

[www.acsa.org.au/savive.html](http://www.acsa.org.au/savive.html)

VICTORIA

**Harm Reduction Victoria**

Tel 03 9329 1500

[www.hrvic.org.au](http://www.hrvic.org.au)

WESTERN AUSTRALIA

**Western Australia Substance Users  
Association (WASUA)**

Tel (08) 9321 2877

[www.wasua.com.au](http://www.wasua.com.au)

**Hepatitis Australia**

[www.hepatitisaustralia.com](http://www.hepatitisaustralia.com)

The Hepatitis Australia website is an information resource for people affected by hepatitis B and C and those who work to support them.

NORTHERN TERRITORY

For injecting equipment, information and support, contact the Northern Territory AIDS and Hepatitis Council (NTAHC)

TASMANIA

For injecting equipment, information and support, contact the Tasmanian Council on AIDS, Hepatitis and Related diseases (TasCAHRD)

## Services for Sex Workers

NATIONAL

### **Australian Sex Workers Association – Scarlet Alliance**

Tel 02 9326 9455

Email: [info@scarletalliance.org.au](mailto:info@scarletalliance.org.au)

[www.scarletalliance.org.au](http://www.scarletalliance.org.au)

AUSTRALIAN CAPITAL TERRITORY

### **SWOP - Sex Workers Outreach Project**

Tel 02 6247 3443

[www.aidsaction.org.au/swop](http://www.aidsaction.org.au/swop)

NEW SOUTH WALES

### **SWOP**

Tel 02 9319 4866

Freecall 1800 622 902

[www.swop.org.au](http://www.swop.org.au)

### **Touching Base Inc**

Touching Base Inc. was developed out of the need to assist people with disabilities and sex workers to connect with each other, focusing on access, discrimination, human rights and legal issues and the attitudinal barriers that these two marginalised communities can face.

**General Enquiries:** [info@touchingbase.org](mailto:info@touchingbase.org)

**Referral List c/-** People with Disabilities Australia Inc:  
[intakeofficer@pwd.org.au](mailto:intakeofficer@pwd.org.au)

**Training and Seminars:**  
[training@touchingbase.org](mailto:training@touchingbase.org)

### **Postal Address:**

P.O. Box 523, Newtown, NSW 2042, Australia

NORTHERN TERRITORY

### **SWOP - Sex Workers Outreach Project**

Tel 08 8944 7777

[www.ntahc.org.au/swop.htm](http://www.ntahc.org.au/swop.htm)

SOUTH AUSTRALIA

### **SIN - South Australian Sex Industry Network**

Tel 08 8334 1666

[info@sin.org.au](mailto:info@sin.org.au)

[www.sin.org.au](http://www.sin.org.au)

VICTORIA

### **Rhed - Resuming Health and Education**

Tel 03 9534 8166

[www.sexworker.org.au](http://www.sexworker.org.au)

WESTERN AUSTRALIA

### **Magenta**

Tel 08 9328 1387

<http://fpwa.org.au/services/magenta/>

QUEENSLAND

### **Crimson Coalition**

PO Box 2470

New Farm

Queensland 4005

Australia

[crimsoncoalitionqld@gmail.com](mailto:crimsoncoalitionqld@gmail.com)

### **United Sex workers North Queensland (USNQ)**

Townsville

(07) 4724 4853

Cairns

0413 571 394

<http://www.scarletalliance.org.au/nm/australia/qld/usnq/>

## Transgender Services

NEW SOUTH WALES

### **The Gender Centre**

Tel: 9569 2366

[www.gendercentre.org.au](http://www.gendercentre.org.au)

### **Seahorse Club (support group)**

Tel: 0423 125 860

Email: [crossdress@seahorsesoc.org](mailto:crossdress@seahorsesoc.org)

[www.seahorsesoc.org](http://www.seahorsesoc.org)

## Health Services

NATIONAL

### Quitnow

www.quitnow.info.au

Quitline: 131 848

### Pulmonary Health Australia (PHA)

www.phaaustralia.com.au

### Heart Foundation Australia

Freecall: 1300 362 787

www.heartfoundation.org.au

### Kidney Health Australia

Freecall: 1800 454 3639

www.kidney.org.au

### Cancer Council Australia

Helpline: 13 11 20

www.cancer.org.au

### Diabetes Australia

1300 136 588

www.diabetesaustralia.com.au

### Osteoporosis Australia

http://www.osteoporosis.org.au

### Nutrition Australia

E: email vic@nutritionaustralia.org.

http://www.nutritionaustralia.com.au

### Australasian Menopause Society

E: ams@netlink.com.au

http://www.menopause.org.au

### National Breast and Ovarian Cancer Centre

Tel 02 9357 9400

E: directorate@nbocc.org.au

http://www.nbcc.org.au

### Breast Cancer Network Australia

Free call: 1800 500 258

E: beacon@bcna.org.au

http://www.bcna.org.au

### BreastScreen Australia

Tel: 13 20 50

http://www.breastscreen.info.au

### Interpreter Services

Telephone Interpreter Service (TIS)

Phone 141 450

## Multicultural and Related Services

### Federation of Ethnic Communities

#### Councils of Australia

www.fecca.org.au/members.cfm

NEW SOUTH WALES

#### Multicultural HIV/AIDS and Hepatitis C Service (MHAHS)

www.multiculturalhivhepc.net.au

Freecall: 1800 108 098

SOUTH AUSTRALIA

#### Personal Education and Community Empowerment (PEACE) Multicultural Services

www.rasa.org.au/RASA/MenuBar/Services/PEACE.aspx

P: (08) 8245 8100

VICTORIA

#### Multicultural Health and Support Service

www.nrhc.com.au/programs/mhss.html

P: 03 9342 9720

#### Alfred Hospital – HIV CALD Service

www.alfredhealth.org.au/hivaidsservice

P: 03 9076 3942

## Aged Care, Advocacy and rights services

### Health Care Complaints Commission

Complaints may be made about anything to do with public or private health care services or a health care practitioner

NSW Free call 1800 043 159

NT Free call 1800 806 380

QLD Toll free 1800 077 308 (outside the Brisbane area)

SA Toll free in SA 1800 232 007

TAS Free call 1800 001 170

VIC Toll Free 1800 136 066

WA Country Free Call 1800 813 583  
(08) 9323 0600

ACT 02 6205 2222

### The National Aged Care Advocacy Program

The National Aged Care Advocacy Program (NACAP) is a free and confidential service promoting the rights of people receiving aged care services and is funded by the Commonwealth Department of Health and Ageing.

T.A.R.S. is part of this National Advocacy Network, which operates in N.S.W. only. If you live elsewhere and would

like to contact agencies in other states or territories please see [www.tars.com.au/NACAP.php](http://www.tars.com.au/NACAP.php) for information on the National Advocacy Network.

#### **Aged Care Australia**

Aged Care Australia provides comprehensive, impartial information about aged care. You'll find information that can help you work out what services are available to help you and how you can get started.

Email: [agedcare.website@health.gov.au](mailto:agedcare.website@health.gov.au)

[www.agedcareaustralia.gov.au](http://www.agedcareaustralia.gov.au)

Freecall: 1800 500 853

#### **Commonwealth Respite and Carelink Centre Program**

Commonwealth Respite and Carelink Centres provide a single point of contact for the general public, service providers, general practitioners and other health professionals for free and confidential information on community, aged and disability services and carer support and respite. The Centres can also assist with information about costs for services, assessment processes and eligibility criteria.

Freecall™ 1800 052 222

#### **Australian Council on the Ageing**

Australia's leading seniors' organisation, with individual members and seniors organisation members in all States and Territories.

Tel 08 8232 0422 or 1800 182 324

Fax 08 8232 0433

Email [cota@cota.org.au](mailto:cota@cota.org.au)

[www.cota.org.au](http://www.cota.org.au)

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**acon**  
BUILDING OUR COMMUNITY'S  
HEALTH & WELLBEING

For more copies of this resource,  
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People Living with HIV Organisation.

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*Past*

*Wellbeing*

*Love*