





YOUR GUIDE TO Living Positively



Our healthcare professionals who run this programme are experts in the management of HIV and will provide you with all the support and information you need.



NOTE

While every effort has been made to ensure the accuracy of the material presented in this booklet, it is for your information and is not a substitute for medical advice. We encourage you to contact your doctor or the HIV **YourLife** Programme counsellors with any questions about your health, treatment or care.

MMI Health (Pty) Ltd, the HIV YourLife Programme, the authors and reviewers will not be held liable for errors, omissions or inaccuracies in this book. It is up to the individual to manage his or her condition appropriately in consultation with his or her doctor.

Welcome

Welcome to the HIV YourLife Programme offered by MMI Health. You have made all the right decisions. You chose to know your status and to join this programme, which will help you live a long and healthy life.

The good news is that modern treatment available for HIV/AIDS means that living with HIV is the same as living with any other chronic condition such as diabetes or high blood pressure. When HIV is closely managed, regularly checked and properly treated, HIV-positive people can live happy, healthy and fulfilling lives. Joining this programme marks your first step towards a positive and productive life. However, it is important that you keep your immune system healthy, your stress levels low and build up a good support system. The healthcare professionals from MMI Health are experts in the management of HIV. They will provide you with the support and information you need to manage your condition.

The information in this booklet explains how the programme works and provides guidance on living positively with HIV. But remember, information is only half the solution. The other half is applying what you know to every part of your life.



Sharing your status

When you first found out that you were HIV positive, did you want to just hide in a corner and not tell anyone? Maybe you did not know HOW to tell other people, even your partner and family members? It is very important that you share your status with others, particularly your partner and/or previous partners, as they could be at risk of infection. They need to know your status so that they can also get tested, know their status and start managing their HIV should they test positive.

Sharing your status with friends and family will also help you to be better prepared mentally and emotionally for living with HIV. It may be hard to know if telling certain people will have good or bad outcomes. You may fear that friends or family will judge you or think of you in a different way. However, opening up about being HIV positive often also means that you can get support, information and acceptance.

Deciding WHO to tell and HOW to tell them may be very difficult. Remember, there is no right way to do this. It is a very personal choice that only you can make. If you are struggling with these decisions, talk to the counsellors on the HIV **YourLife** Programme. They have a great deal of experience to share with you and will be able to give you sound advice.

Are my family members at risk?

The HIV virus is transmitted through exposure to body fluids from an infected person. Proper precautions must be taken where necessary, for example, during sex and when preparing food. Care must be taken to avoid penetrating injuries that may result in exposure to infected blood or other infected body fluids. If you are concerned about this at any time, contact the case managers on the HIV YourLife Programme for guidance. They will provide advice if a family member may have been exposed to the virus and may need post-exposure prophylaxis (PEP) medication to prevent HIV infection.

My HIV YourLife Programme

Who manages my HIV YourLife Programme?

The HIV YourLife Programme was developed by MMI Health and is run by the healthcare professionals who are all specialists in the field of HIV management. MMI Health is one of the leading managed healthcare companies in South Africa and invests a great deal in ensuring that the HIV YourLife Programme is based on the latest available research and information on the effective treatment and management of HIV/AIDS.



It's all completely confidential

One very important characteristic of the HIV YourLife Programme is that it is completely confidential. Interaction between you and our case managers is 100% confidential. Information on your status and anything you share with us will <u>never</u> be passed on to your employer, colleagues, family members or anyone else without your permission.

What can I expect from the HIV YourLife Programme?

You can expect to receive:

- » information and advice on treatment
- » counselling from experienced healthcare professionals
- » continuous support and encouragement from people who genuinely care and understand
- » information about the correct diet, vitamins and lifestyle to build your immune system
- » referrals to healthcare providers who are specialists and experienced in managing HIV patients
- with your permission, counselling and support for your family members and sexual partner
- » access to treatment for HIV/AIDS and tuberculosis (TB).

What happens when I call the HIV YourLife Programme?

- » A qualified and experienced healthcare professional will explain how the programme works and the benefits available to you.
- » They will also explain the steps you need to follow should you wish to join the programme.



REMEMBER:

MMI Health will never share any of your personal details with your employer. Everything related to your participation on the programme is completely confidential. MMI Health is not linked to your employer in any way.

What medical benefits am I covered for through the programme?

You are covered for the following benefits on the programme:

- » Antiretroviral medication
- » Blood tests related to HIV/AIDS
- » Doctors' consultations
- » If you are pregnant, treatment to help prevent your baby from contracting the HIV virus
- » Post-exposure prophylaxis (PEP) medication to prevent HIV infection if you are exposed to blood or fluids from an infected person or by any other means
- » Management of TB for those who need it.

How do I get my medication through the programme?

Contact one of our experienced case managers on the HIV YourLife Programme who will guide you through the process for obtaining your medication. Alternatively your doctor may call us with your prescription and we will authorise the medication. You can then choose to have the medication delivered to your home by a courier pharmacy or to collect it from your nearest pharmacy.

My antiretroviral therapy (ART)

What is ART?

The medication used to control HIV is called antiretroviral medication or ARVs. ('Antiretroviral' refers to the fact that the HIV virus is also called a retrovirus.) A combination (mixture) of ARVs is called antiretroviral therapy (ART) and is taken to lower the levels of HIV in the body. This allows the immune system to partially recover and prevent further damage to the body.

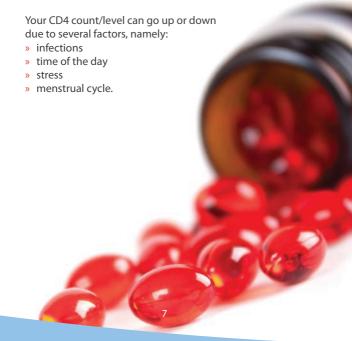
It is important to note that ART is not a cure for AIDS. However, ART attacks the HIV itself, interfering with the way the virus tries to reproduce itself inside a human cell. In this way they help make your immune system stronger so that you can be healthier. They are also very important in helping your body to fight off and prevent 'opportunistic' illnesses such as pneumonia, TB and diarrhoea. Opportunistic illnesses are illnesses that tend to develop when certain viruses, such as HIV, weaken our immune system. Refer to page 12 for more information on opportunistic illnesses.

How will I know if ART is working for me?

The following tests are used to monitor how well the antiretroviral medication is working:

CD4 count

A CD4 count checks your number of CD4 cells. CD4 cells ensure that your immune system works properly. They are the body's fighter cells, protecting the body against infecting viruses or bacteria. The lower your CD4 count, the more damaged your immune system is. If the ART is working well, you will have more CD4 cells to fight infection in your body. This is a sign that your immune system is getting stronger. If your CD4 count was less than 50 when you started ART, it may not increase very much in the beginning, but you will still start to feel better.



Viral load

Viral load is a measure of the amount of HIV a person has in their blood. A high viral load indicates a high level of infection, which means the condition will develop quicker. The viral load test checks if the amount of HIV in your body is decreasing. Ideally, your viral load should decrease to a level where no virus can be detected by the test.

The CD4 and viral load tests are used together to track the damage HIV has done to your immune system, as well as your response to antiretroviral medication.

Apart from these test results, an important sign that your ART is working is that you will start to feel healthier, stronger and have more energy. Your immune system will be stronger and you won't get sick as often as you did before you went on ART. Your cough, thrush, rash or diarrhoea may go away. If you lost weight, you will start to regain some weight and your appetite will improve.



REMEMBER:

ART cannot cure or remove HIV from the body completely, even if the blood test shows that there is no virus. If you stop taking your ARVs, the virus will start to increase again. It is always very important for you to keep on taking your ARV medication as prescribed.



Follow-up appointment reminder

		APPOINTMENT 1	APPOINTMENT 2 APPOINTMENT 3	APPOINTMENT 3	APPOINTMENT 4	APPOINTMENT 5	APPOINTMENT 6
	CD4	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY DD/MM/YYYY DD/MM/YYYY DD/MM/YYYYY DD/MM/YYYYY DD/MM/YYYYY	DD/MM/YYYY	DD/MM/YYYY
	CD4 results	cells/µl	cells/µl	cells/µl	cells/µl	cells/µl	cells/µl
	Viral load	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY DD/MM/YYYY DD/MM/YYYY DD/MM/YYYY DD/MM/YYYY DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY
9	Viral load results	copies	copies	copies	copies	copies	copies
		APPOINTMENT 7	APPOINTMENT 8	APPOINTMENT 9	APPOINTMENT 9 APPOINTMENT 10 APPOINTMENT 11 APPOINTMENT 12	APPOINTMENT 11	APPOINTMENT 12
	CD4	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY DD/MM/YYYY DD/MM/YYYY DD/MM/YYYY DD/MM/YYYY DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY
	CD4 results	cells/µl	cells/µl	cells/µl	cells/µl	cells/µl	cells/µl
	Viral load	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY DD/MM/YYYY DD/MM/YYYY DD/MM/YYYY DD/MM/YYYY DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY
	Viral load results	copies	copies	copies	copies	copies	copies

Treatment plan

You need to go for the following routine check-ups and blood tests based on your risk status:

RISK STATUS	FREQUENCY OF DOCTOR VISITS	BLOOD TESTS REQUIRED
Not yet on antiretroviral treatment	Twice a year	CD4 count, viral load, ALT*, AST**, serum creatinine and full blood count
On antiretroviral treatment	Every four to six months	CD4 count, viral load, ALT, AST, serum creatinine, full blood count and other relevant tests depending on type of antiretroviral treatment
Side-effects/weight loss/changes in body shape	Contact your case manager	Dependent on signs and symptoms
Pregnant	Contact your doctor and case manager as soon as possible	Pregnancy test and other relevant tests

Alanine aminotransferase (ALT*) and aspartate transaminase (AST**) are enzymes that are normally present in liver cells.

Medication reminder chart

Name:					
MEDICATION NAME	INSTRUCTION	MORNING	MORNING AFTERNOON EVENING	EVENING	NIGHT
Stocrin*	1 tablet at night	1	1	1	1

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Sticking to your prescribed medication routine is absolutely vital!

*Note: This is only an example

We cannot stress how important it is to stick to the antiretroviral therapy your doctor prescribes. Like any medication, it is essential that you take your ARVs every day as required for it to be able to work the way it should, and to provide you with the best health

Opportunistic infections and HIV

Our bodies carry various germs, bacteria, fungi and viruses. When our immune system is working, it controls these germs. However, when our immune system is weakened by the HIV virus, these germs can get out of control and cause health problems.

Infections that take advantage of weaknesses in the immune system are called 'opportunistic' infections. Some of the opportunistic infections that can develop when the HIV virus weakens our immune system are:

- » candidiasis (thrush) a fungal infection of the mouth, throat, or vagina
- » cytomegalovirus (CMV) a viral infection that causes eye disease that may lead to blindness
- » herpes simplex viruses can cause oral herpes (cold sores) or genital herpes
- » malaria this condition is more common and more severe in people with HIV infection
- » mycobacterium avium complex (MAC or MAI) a bacterial infection that can cause recurring fevers, problems with digestion, serious weight loss and generally feeling unwell
- » pneumocystis pneumonia (PCP) a fungal infection of the lungs that can cause fatal pneumonia
- » toxoplasmosis (TOXO) a parasitic infection of the brain
- » tuberculosis (TB) a bacterial infection that attacks the lungs and may cause meningitis.

Your HIV YourLife Programme will help to prevent opportunistic infections. If you are already suffering from an opportunistic infection, in addition to HIV, the case managers on the HIV YourLife Programme and your doctor will work together to ensure that you receive the right treatment in this case.

TB screening tool

TB co-infection is common in patients that have a compromised immune system. All HIV-positive patients should therefore be screened for TB on a regular basis. Complete the questionnaire below to assess your risk of TB infection.

TB screening questions Please tick the appropriate block

	YES	NO
Have you been experiencing any of the following:		
Coughing for more than two weeks?		
Mucous production which may occasionally be blood stained?		
Fever for more than two weeks?		
Very bad night sweats?		
Unexplained weight loss of more than 5 kg in a month?		
General feeling of illness and tiredness?		
Chest pain or difficulty breathing?		
Have you been in contact with someone who you think may have TB?		

If you answered 'yes' to any of the above, you should make an appointment with your doctor for further diagnostic tests to exclude TB.



My healthy lifestyle

Once you have dealt with an HIV-positive diagnosis, it is time to make lifestyle changes in order to stay healthier for longer. Living positively with HIV means living a healthy life, filled with happiness and hope for the future.

Sometimes we only think of our health in terms of our physical health. However, good health has many aspects and our emotional health is also very important.

Take care of your physical health

You can care for your physical health in the following ways:

» Follow a balanced diet

We all know it is important to follow a healthy, balanced diet, but this becomes even more important when you are HIV positive. Nutrition is an area where you'll need to pay special attention because your body will undergo changes; both from the medication you will be taking and the HIV itself. You may experience extreme weight loss, infections or diarrhoea. Another common change is lipodystrophy (fat distribution syndrome), which can cause changes in your body shape and increase your cholesterol levels. Making improvements to your diet can improve your health and the way you feel.

While dietary advice should be tailored to each individual's needs, in general the recommendations for people who are HIV positive are much the same as for everyone else, namely a healthy, balanced diet.



There are however important differences that you need to be aware of. These include:

- » People who are HIV positive often tend to lose weight. One factor behind HIV-related weight loss is increased energy expenditure. Studies have found that people with HIV tend to burn around 10% more calories while resting, compared to those who are uninfected.
- » The weight lost during HIV infection tends to be in the form of lean tissue, such as muscle. This means there may be changes in your body shape, even if the overall weight stays the same.
- » People who are HIV positive may also lose weight due to infections that lead to loss of appetite and affect their ability to eat. For example, sores in the mouth or throat may cause pain when swallowing, while diarrhoea or nausea may disturb normal eating patterns. Helpful suggestions include eating several small meals per day, exercising to stimulate your appetite, possibly mashing or liquidising food to ease swallowing and seeking advice from your doctor or the counsellors on the HIV YourLife Programme.

The basics of good nutrition

Remember to follow the basic principles of healthy eating as they will serve you well. These include:

- » eating a diet high in fruit, vegetables, whole grains and legumes including proteins, carbohydrates and a little fat in all meals
- » choosing lean, low-fat sources of protein
- » avoiding sweets, soft drinks and foods with added sugar
- » avoiding junk food, caffeine, alcohol, smoking and drugs, as these will suppress your immune system.

The benefits of good nutrition

Good nutrition is very important for people living with HIV/AIDS because it:

- » improves your overall quality of life by providing the nutrients your body needs
- » keeps your immune system stronger so you can better fight infections
- » helps to manage HIV symptoms and complications
- » processes medication and helps to manage their side effects.

Vitamins and supplements

Vitamin supplements and immune boosters can be taken to supplement your health. Micronutrients are vitamins and minerals that the body needs to maintain good health. Research has found that people who are HIV positive are more likely to show signs of micronutrient deficiencies, compared to uninfected people. More specifically, low levels of vitamin A, vitamin B12, vitamin C, vitamin D, selenium, zinc and iron tend to occur amongst HIV-positive people.

A good multivitamin (an immune booster) can be taken to supplement your health. However there are some important things to remember when taking these supplements:

- » It is important to understand that vitamins will not prevent or reverse AIDS. The South African Department of Health's (DOH) guidelines on nutrition for people with HIV/AIDS make it clear that "vitamins are not a treatment for the disease".
- » It is also important to remember that multivitamins are not a substitute for food. Don't think that by taking vitamins, it is now okay to skip meals or eat less. It is also very important that you take vitamins after meals.
- » Vitamins can cause side-effects if taken in large doses. For example, too much vitamin C can cause diarrhoea. It is therefore vital that you speak to your doctor or the HIV YourLife Programme counsellors on the types and amount of vitamins and supplements you should take.



- » There are many reasons for giving up alcohol when you are HIV positive. One such reason is that alcohol reduces the benefit we get from vitamins. It is always advisable to consult your doctor before taking vitamin supplements and/or immune boosters if you are HIV positive, especially when taking antiretroviral medication.
- » Immune boosters are said to stimulate the production of white blood cells, which are the cells of the immune system that fight invading bacteria and viruses. However it is important to note that there are different types of white blood cells; HIV targets only one type of these cells – the T-helper cell. This makes the administration and functioning of immune boosters quite complex and it is therefore very important that you discuss the use of immune boosters with your doctor or your HIV YourLife Programme counsellor.

» Get enough sleep

Fatigue suppresses your immune system so regular, good sleep in sufficient quantities is essential.

» Exercise regularly

While exercise and physical activity are very important for your health, it doesn't mean you have to join the gym. Walking, doing household chores or riding a bike are all great ways of staying active.

Try to choose activities you enjoy. This could be dancing, playing soccer, walking, swimming, jogging – whatever works for you. If you can fit physical activity into each day, it will uplift your mood and improve your health. Regular exercise also helps to:

- » relieve your stress
- » improve your appetite
- » strengthen and build your muscles so that they can store energy and protein that your body can use when fighting infection
- » improve your sleep
- » improve your self-esteem.

» Always practice safe sex to prevent re-infection.



Take care of your emotional health

In addition to taking care of your physical health, it is also very important to look after your emotional health. Here are some tips to bear in mind:

» Managing your anxiety

If you are concerned about any changes in your physical health, you should consult your doctor or the case managers on the HIV **YourLife** Programme to calm your fears. Discuss your feelings with your case manager and be sure to get as much information as possible.

» Reducing isolation

You do not need to disclose your HIV status to everyone. Instead, start by identifying a small number of trusted people who you know will be supportive and helpful. The counsellors on the HIV YourLife Programme will always be available to support you. In addition, you could consider joining a support group. Research has shown that accessing and receiving support have great health benefits such as reducing symptoms and improving your quality of life.

» Managing your depression

If you feel depressed for more than two weeks, you should consult your doctor or the counsellors on the HIV **YourLife** Programme. Treatment is available so there is no need to deal with depression on your own.

» Managing your anger

If you are constantly feeling angry, it may be a good idea to speak to a counsellor to assist you in processing and managing your anger. Other useful tips for managing anger include regular exercise and meditation.

» Overcoming denial

HIV is not a death sentence. By changing your lifestyle and living healthily, you can live a normal life. Counselling will help you work towards a level of acceptance that will motivate you to make the necessary changes that can benefit your life.

Managing illness

Diarrhoea

Diarrhoea is the rapid passage of stool through the intestines and can result in the body not retaining enough water or food. If left untreated it can cause serious health problems and could lead to dehydration. You can manage diarrhoea by following these simple rules:

- » Eat bland foods such as rice, dry toast, bananas or crackers.
- » Eat foods high in protein, calories and potassium.
- » Drink eight to 12 glasses of clear fluids each day, such as water, juice and low-salt soup. Remember to rest when you are tired.

Constipation

Constipation refers to infrequent bowel movements and may be caused by many factors. These could include using certain medication, eating mostly soft or liquid foods which are low in fibre, and/or being less physically active. Manage constipation by drinking at least eight to 10 glasses of water a day, increase your intake of fibre and exercise to help ease the constipation (e.g. take a walk if you feel up to it).

Nausea

Nausea is an uneasiness of the stomach that often precedes/leads to vomiting. Nausea is a common side effect of many medications used to manage HIV. Consider these tips to help manage nausea:

- » Sip cool (not cold) carbonated drinks, such as ginger ale, 7-Up, Sprite or cola, or try some peppermint, chamomile or ginger tea.
- » Avoid spicy, strong-smelling foods and prevent dehydration by drinking small amounts of clear and cool beverages every 15 minutes.
- » If you do start vomiting, seek medical advice and replace lost fluids with rehydration fluids.

Sore throat

The mouth and throat are common target areas for certain infections such as candidiasis (thrush) or herpes. You can manage the discomfort of a sore throat by:

- » choosing smooth foods such as soup, mashed potatoes, custard, jelly, etc.
- » avoiding acidic food such as pineapples, tomatoes and citrus fruit
- » drinking lots of water, apple juice or black tea gargling with salt water is also a good way to reduce swelling and irritation.

Circumcision

What is circumcision?

Circumcision is a surgical procedure performed on males whereby the foreskin of the penis is removed. Ideally, circumcision is performed on infant males, however many adult males may be circumcised for medical, cultural or religious reasons. An adult male may also make a personal decision to have a circumcision.

Why do we recommend circumcision?

A man's foreskin traps bacteria and the combination of high humidity, relative lack of oxygen and the harbouring of germs could potentially activate cells that promote HIV infection. Evidence-based studies have shown that circumcision has a protective effect against HIV infection in men. We recommend and would advise that all adult males be circumcised as this procedure improves

personal hygiene and reduces the risk of contracting HIV. Circumcision is recommended as a preventative method in addition to practicing safe sex (which includes single partner sex, known partner status and the use of condoms).

Protection from HIV

An uncircumcised man is at greater risk of contracting HIV if he practices unsafe sex. Therefore, condoms should always be used during sexual intercourse irrespective of your HIV or circumcision status.

Risks and recovery

All surgery involves some level of risk; however circumcision is a low-risk procedure with a complication rate of 1%. There may be swelling afterwards and sensitivity around the affected area. Although recovery may take a week or two, it is recommended that you abstain from sexual intercourse for a period of six weeks after the procedure.



B the Future cellbook

The *B the Future* cellbook was developed by the MMI Foundation. It is designed to encourage South Africans to know their HIV status and to take responsibility for managing their health. Once downloaded it remains on your phone for easy, quick and private access to HIV/AIDS information. It typically takes up less space than a ringtone (only around 300Kb) and you only need to download it once. It contains comprehensive information on HIV/AIDS, including how to prevent HIV infection, how to test for HIV, how to manage your positive status and where to obtain support and counselling.



Together we can beat HIV and AIDS.



Contact us

If you have any other questions that were not answered in this booklet, please contact the HIV **YourLife** Programme.

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How are you participating in 'Getting to Zero'?

