

HIV&AIDS and its Treatment Information Pack: What you Should Know

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Last but not least, we extend our thanks to all organizations working at the community level who address the needs of people living with HIV&AIDS from whom we have drawn valuable insights. We value your work at the community level.

Allan Ragi
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Introduction

During the last five years, HIV&AIDS treatment has begun to become more available and accessible to more people living with HIV within Sub-Saharan Africa which bears the blunt of the pandemic. This has been supported by various international initiatives such as the World Health Organisation 3 x 5 initiative, the Millennium Development Goals and the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) Declaration of Commitment and currently the Principle of Universal Access by the G8. These commitments have seen the cost of treatment especially anti-retroviral drugs go down and hence their use has increased in the resource constrained countries.

Kenya has made great strides in increasing access to treatment to thousands of people living with HIV even though much more needs to be done to make this a reality for all those who need these crucial services. However besides availing drugs and other therapeutic products and services, it is important for people living with HIV, affected families and communities as well as care providers to be equipped with information on the treatment options and requirements. This information package is therefore designed to provide crucial information in a simplified manner to a diversity of audiences especially those living with HIV and care providers working at community level.

The information package starts off by providing information on the difference between HIV infection and developing AIDS. It explains how HIV attacks the immune system and the opportunistic infections that arise due to HIV infection. This chapter sets the base upon which other chapters addressing treatment and care concerns for people living with HIV are built.

The second chapter explores the meaning of treatment and also the tests that are necessary before treatment commences. Issues on how to know whether one is ready for treatment are also addressed. Chapter three and four look at commencing HIV treatment including the available treatment options and regimens. They provide insight into the approved drugs and also the possible side effects of the anti-HIV treatment as well as how to know whether the treatment is working well for the individual person receiving it.

The fifth chapter discusses treatment failure, how it is identified, its causes and how it can be dealt with while Chapter six focuses on changing the treatment regimen. The seventh chapter deals with adherence to treatment. The importance of adherence,

reasons why people on anti-HIV treatment find it difficult to adhere and how one can improve the adherence to treatment are explored.

Chapter eight looks at HIV/AIDS and pregnancy. Issues including what medication women who are pregnant should take, if they are already on anti-retroviral therapy whether they should change their regimen as well as how to protect their unborn babies from HIV infection are addressed. In Chapter nine, HIV prevention for people who are living with HIV is deliberated on. This includes the meaning of prevention, how they can protect their partners and the need to disclose their sero-status to their partners. The question of undetectable viral load is also addressed.

Chapter ten discusses the alternative therapies besides western conventional medicine. These range from methods that are commonly utilized in Kenya such as herbal medicine, mind to lesser common methods such as body therapies, acupuncture and homeopathy which are practices to a limited extent since they are mainly developed from oriental countries but they have found a niche in the Kenyan communities. The eleventh chapter discussed Nutrition as an integral part of HIV treatment. People living with HIV need proper nutrition in order to boost their immunity and also to be strong enough to handle the effects of the treatment that they are taking. In this chapter the importance of nutrition to people living with HIV is underscored. The need for having a proper diet which includes the vital nutrient is emphasized and the relationship between proper nutrition and the immune system is also discussed.

By developing this package, KANCO hopes to increase the knowledge of people living with HIV, affected families, communities and community care givers on HIV/AIDS treatment and management. It is hoped that the simplified messages can help all those of are involved in caring and supporting people living with HIV to strengthen the uptake and sustainability of treatment and also be able to link with health care providers and clinicians in addressing issues related to treatment.

Testing HIV Positive – Do I Have AIDS?

I tested HIV positive. What does this mean? Does it mean I have AIDS?

A positive HIV test result means that you are infected with HIV (Human Immunodeficiency Virus), the virus that causes AIDS (Acquired Immune Deficiency Syndrome). Being infected with HIV does not mean that you have AIDS right now. However, if left untreated, HIV infection damages a person's immune system and can progress to AIDS.

What is AIDS?

AIDS is the most advanced stage of HIV infection. It results from the destruction of the infected person's immune system. Your immune system is your body's defence system. Cells of your immune system fight off infection and other diseases. If your immune system does not work well, you are at risk of serious and life-threatening infections and cancers. HIV attacks and destroys the disease-fighting cells of the immune system, leaving the body with a weakened defence against infections and common diseases.

Which disease-fighting cells does HIV attack?

CD4 cells are a type of white blood cells that fights infections. They are also called CD4⁺ T cells or CD4 T lymphocytes. When HIV enters a person's CD4 cells, it uses the cells to make copies of itself. The cell then breaks and these new HIV particles are released into the blood stream. This process destroys the CD4 cells, and the CD4 count goes down. As you lose CD4 cells, your immune system becomes weak. A weakened immune system makes it harder for your body to fight infections.

How will I know if I have AIDS?

AIDS is not a diagnosis you can make yourself; it is diagnosed when the immune system is severely weakened. If you are infected with HIV and your CD4 count drops below 200 cells/mm³, or if you develop an AIDS-defining condition (an illness that is very unusual in someone who is not infected with HIV), you have AIDS.

What are the AIDS-defining conditions?

In December 1992, the Centers for Disease Control and Prevention (CDC) published the most current list of AIDS-defining conditions*. The AIDS-defining conditions are:

- Candidiasis (Thrush, yeast infection)
- Cervical cancer (invasive)
- Coccidioidomycosis, Cryptococcosis, Cryptosporidiosis
- Cytomegalovirus disease
- Encephalopathy (HIV-related)
- Herpes simplex (severe infection)
- Histoplasmosis
- Isosporiasis
- Kaposi's sarcoma
- Lymphoma (certain types)
- Mycobacterium avium complex
- Pneumocystis carinii pneumonia
- Pneumonia (recurrent)
- Progressive multifocal leukoencephalopathy
- Salmonella septicemia (recurrent)
- Toxoplasmosis of the brain
- Tuberculosis (TB)
- Wasting syndrome
- And other infections

NB: People who are not infected with HIV may also develop these diseases; this does not mean they have AIDS. To be diagnosed with AIDS, a person must be infected with HIV.

Key Terms Used in This Chapter

AIDS: Acquired Immune Deficiency Syndrome. AIDS is the most severe form of HIV infection. HIV infected patients are diagnosed with AIDS when their CD4 count cell counts fall below 200 cells/mm³ or they develop an AIDS-defining illness (an illness that is very unusual in someone who is not HIV positive).

What is HIV treatment?

HIV treatment is the use of medications to keep an HIV infected person healthy. Treatment can help people at all stages of HIV disease. Although anti-HIV medications can treat HIV infection, they cannot cure HIV infection. HIV treatment is complicated and must be tailored to you and your needs. Anti-HIV medication is also referred to as anti-retroviral drugs (ARVs).

Seeing an HIV Doctor

I am HIV positive. What kind of doctor do I need?

Your doctor (or other healthcare provider) should be experienced in treating HIV and AIDS. You may want to see an infectious disease specialist. You will need to work closely with your doctor to make informed decisions about your treatment, so it is important to find a doctor with whom you are comfortable.

What can I expect at the doctor's office?

Your doctor will ask you questions about your health, do a physical exam, and order blood tests. This is a good time to ask your doctor questions. Write down any questions you have and take them with you to your appointment.

What questions should I ask my doctor?

You should ask your doctor about:

- Risks and benefits of HIV treatment
- Other diseases you may be at risk of
- How your lifestyle will change with HIV infection
- How you can avoid transmitting HIV to others
- How you can achieve and maintain a healthier lifestyle

What tests will my doctor order?

It is very important to have a CD4 count and a viral load test done at your first doctor's visit. The results will provide a baseline measurement for future tests.

- *CD4 count* – A CD4 count is the number of CD4 cells in a sample of blood.
- *Viral load test* – A viral load test measures the amount of HIV in a sample of blood. This test shows how well your immune system is controlling the virus.

The two viral load tests commonly used for HIV are:

- HIV RNA amplification (RT-PCR) test
- Branched chain DNA (bDNA) test

To ensure accurate results, viral load testing should be done at two different times, by the same laboratory, using the same type of test. The results of different types of tests may differ.

Your doctor may also order:

- Complete blood count
- Blood chemistry profile (including liver function tests)
- Tests for other sexually transmitted diseases (STDs)
- Tests for other infections, such as hepatitis, tuberculosis, or toxoplasmosis

Am I ready to begin HIV treatment?

Once you begin taking anti-HIV medications, you may need to continue taking them for the rest of your life. Deciding when or if to begin treatment depends on your health and your readiness to follow a treatment regimen that may be complicated. You and your doctor should discuss your readiness to begin treatment as well as strategies to make your treatment work for you

If my doctor and I decide to delay treatment, will I need to have my CD4 count and viral load tested again?

Yes. HIV infected people who have not started drug therapy should have a viral load test every 3 to 4 months and a CD4 count every 3 to 6 months. You and your doctor will use the test results to monitor your infection and to decide when to start treatment.

Key Terms Used in This Chapter

Baseline measurement: an initial measurement (such as CD4 count or viral load) made before starting therapy and used as a reference point to monitor your HIV infection.

Liver function tests: these tests measure the levels of liver enzymes (proteins made and used by the liver) to determine if your liver is working properly.

Anti-retroviral drugs (ARVs): These are the medications that are used to suppress the ability of HIV to multiply in the body hence. However ARVs do not cure HIV infection.

Starting Anti-HIV Medications

I am HIV positive. Do I need to take anti-HIV medications?

You do not necessarily need to take anti-HIV medications just because you are HIV positive. You and your doctor will determine the best time to start treatment. When to take anti-HIV medications depends on your overall health, the amount of virus in your blood (viral load), and how well your immune system is working.

How will I know when to start anti-HIV medications?

You and your doctor should consider three factors in deciding when to start treatment: 1) symptoms of advanced HIV disease, 2) viral load, and 3) CD4 count.

You should start treatment if:

- you are experiencing severe symptoms of HIV infection or have been diagnosed with AIDS
- your viral load is 55,000 copies/mL or more
- your CD4 count is 200 cells/mm³ or less

You may also consider starting treatment if your CD4 count is between 200 and 350 cells/mm³; this is something you should discuss with your doctor.

If the anti-HIV medications can help me stay healthy, why wait to start treatment?

Once you begin treatment, you need to continue taking anti-HIV medications for the rest of your life. Although newer anti-HIV medications are easier to take, starting treatment usually means a significant adjustment in your lifestyle. Some anti-HIV medications need to be taken several times a day at specific times and may require a change in meals and mealtimes.

In addition to their desired effects, anti-HIV medications may have negative side effects, some of which are serious. If the virus is not suppressed completely, drug resistance can develop. Side effects and drug resistance may limit your future treatment choices.

What treatment is right for me?

The Ministry of Health through Kenya National AIDS and STDs Control Programme (NASCO) has recommend anti-HIV medications options for adults and children. NASCO provides HIV treatment guidelines on administration and use of these medications. These guidelines recommend that you take a combination of three or more medications in a regimen called **Highly Active Antiretroviral Therapy (HAART)**. The guidelines list “preferred” HAART regimens. However, your regimen should be tailored to your needs. Factors to consider in selecting a treatment regimen include:

- number of pills
- how often the pills must be taken
- if pills can be taken with or without food
- how the medications interact with one another
- other medications you take
- other diseases or conditions
- pregnancy

Recommended HIV Treatment Regimens

When I start treatment, what kinds of medications will I need to take?

Anti-HIV medications are used to control the reproduction of the virus and to slow the progression of HIV disease. Anti-HIV medications are also called antiretroviral drugs. There are four classes of approved antiretroviral medications: Nucleotide Reverse Transcriptase Inhibitor (NRTIs), Non-Nucleotide Reverse Transcriptase Inhibitor (NNRTIs), Protease Inhibitors (PIs), and fusion inhibitors. They are grouped according to how they work in the body.

How many medications will I need to take?

The recommended treatment for HIV is a combination of three or more medications in a regimen called **Highly Active Antiretroviral Therapy (HAART)**. How many pills you will need to take and how often you will take them depends on what medications you and your doctor choose.

Which medications should I take?

Each HAART regimen is tailored to the individual patient – there is no one “best” regimen. You and your doctor will decide which medications are right for you. For people taking HAART for the first time, the regimens recommended by Kenya National AIDS and STD Control Programme (NASCOOP) are:

- Stavudine + Lamivudine + Nevirapine
- Stavudine + Lamivudine + Efavirenz

Are there any other treatment regimens?

Some people may benefit from a different regimen. Recommended alternative regimens are:

- Sustiva + Epivir + (Retrovir or Viread or Zerit)
- Kaletra + Epivir + (Retrovir or Zerit)
- Sustiva + Emtriva + (Retrovir or Viread or Zerit)
- Sustiva + Videx + (Epivir or Emtriva)
- Viramune + (Epivir or Emtriva) + (Retrovir or Zerit or Videx)
- Agenerase + low dose Norvir + (Epivir or Emtriva) + (Retrovir or Zerit)
- Reyataz + (Epivir or Emtriva) + (Retrovir or Zerit)
- Crixivan + (Epivir or Emtriva) + (Retrovir or Zerit)
- Crixivan + low dose Norvir + (Epivir or Emtriva) + (Retrovir or Zerit)
- Kaletra + Emtriva + (Retrovir or Zerit)
- Viracept + (Epivir or Emtriva) + (Retrovir or Zerit)
- (Fortovase or Invirase) + low dose Norvir + (Epivir or Emtriva) + (Retrovir or Zerit)

In general, taking only one or two drugs is not recommended because any decrease in viral load is almost always temporary without three or more drugs. The exception is the recommendation for pregnant women, who may take Retrovir alone or with other drugs to reduce the risk of passing HIV to their infants. A Pregnant woman needs to discuss with her doctor on what regimen to take.

What are some of the negative side effects of HAART?

You may experience negative side effects (drug toxicity) when you take HIV drugs. Some of these side effects are serious, even life-threatening; you may have to change drugs due to intolerable side effects. You and your doctor should discuss the side effects of each medication.

Possible side effects of HAART include:

- liver problems
- diabetes
- abnormal fat distribution (lipodystrophy syndrome)
- high cholesterol
- increased bleeding in patients with haemophilia
- decreased bone density
- skin rash
- pancreatitis (inflammation of the pancreas)
- nerve problems

Side effects that may seem minor, such as fever, nausea, and fatigue, can mean there are serious problems. Always discuss any side effects you are having with your doctor.

Terms Used in This Chapter

Antiretroviral: a medication that interferes with replication of **Antiretroviral:** a medication that interferes with replication of retroviruses. HIV is a retrovirus.

Drug Toxicity: the harm a medication can do to your body.

Drug Resistance: HIV can mutate (change form) while a person is taking anti-HIV medication. This may result in a new strain of HIV that cannot be controlled with medication.

Viral Load: the amount of HIV in a sample of blood.

Approved Medications to Treat HIV Infection

Anti-HIV (also called antiretroviral) medications are used to control the reproduction of the virus and to slow the progression of HIV-related disease. Highly Active Antiretroviral Therapy (HAART) is the recommended treatment for HIV infection. HAART combines three or more anti-HIV medications in a daily regimen. Anti-HIV medications do not cure HIV infection and individuals taking these medications can still transmit HIV to others.

Anti-HIV medications that have been approved fall into four classes:

Class	Generic Name	Brand and Other Names	Manufacturer
Non-nucleoside Reverse Transcriptase Inhibitors (NNRTIs)			
<i>NNRTIs bind to and disable reverse transcriptase, a protein that HIV needs to make more copies of itself.</i>			
Delavirdine	Rescriptor, DLV	Pfizer	
Efavirenz	Sustiva, EFV	Bristol-Myers Squibb	
Nevirapine	Viramune, NVP	Boehringer Ingelheim	
Nucleoside Reverse Transcriptase Inhibitors (NRTIs)			
<i>NRTIs are faulty versions of building blocks that HIV needs to make more copies of itself. When HIV uses an NRTI instead of a normal building block, reproduction of the virus is stalled.</i>			
Abacavir	Ziagen, ABC	GlaxoSmithKline	
Abacavir, Lamivudine, Zidovudine	Trizivir	GlaxoSmithKline	

Didanosine	Videx, ddl Videx EC	Bristol-Myers Squibb
Emtricitabine	Emtriva, FTC, Coviracil	Gilead Sciences
Lamivudine	Epivir, 3TC	GlaxoSmithKline
Lamivudine, Zidovudine	Combivir	GlaxoSmithKline
Stavudine	Zerit, d4T	Bristol-Myers Squibb
Tenofovir DF	Viread, TDF	Gilead Sciences
Zalcitabine	Hivid, ddC	Hoffman-La Roche
Zidovudine	Retrovir, AZT, ZDV	GlaxoSmithKline

Protease Inhibitors (PIs)

PIs disable protease, a protein that HIV needs to make more copies of itself.

Amprenavir	Agenerase, APV	GlaxoSmithKline, Vertex Pharmaceuticals
Atazanavir	Reyataz, ATV	Bristol-Myers Squibb
Fosamprenavir	Lexiva, FPV	GlaxoSmithKline, Vertex Pharmaceuticals
Indinavir	Crixivan, IDV	Merck
Lopinavir, Ritonavir	Kaletra, LPV/r	Abbott Laboratories
Nelfinavir	Viracept, NFV	Agouron Pharmaceuticals

Ritonavir	Norvir, RTV	Abbott Laboratories
Saquinavir	Fortovase, SQV Invirase	Hoffman-La Roche

Fusion Inhibitors

Fusion Inhibitors prevent HIV entry into cells.

Enfuvirtide	Fuzeon, T-20	Hoffman-La Roche, Trimeris
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It is important to note that these ARVs may be produced by different manufacturers in as generic drugs.

Is My Treatment Regimen Working?

How will I know if my HIV treatment regimen is working?

In general, viral load is the most important indicator of how well your regimen is working. Your viral load should decrease if your medications are effective. Other factors that can tell you and your doctor how well your regimen is working are:

- Your CD4 count. This should remain stable or go up if your drugs are working.
- Your recent health and results of physical examinations. Your treatment regimen should help keep you healthy.

How often should I have a viral load test?

Your viral load should be tested 2 to 8 weeks after you start treatment, then every 3 to 4 months throughout treatment to make sure your drugs are still working. HIV treatment can reduce your viral load to the point at which it is undetectable. An undetectable viral load does not mean that your HIV infection is gone; it simply means that the test is not sensitive enough to detect the small amount of HIV left in your blood.

If your viral load is still detectable within 4 to 6 months after starting treatment, you and your doctor should discuss how well you have adhered to your regimen. Missing medication doses is the most common reason for treatment failure and development of drug resistance. Your doctor should do a drug resistance test, which will determine if the HIV in your body has mutated into a strain that your current treatment regimen can't control.

How fast or how much your viral load decreases depends on factors other than your treatment regimen. These factors include your baseline viral load and CD4 count, whether you have taken HIV drugs before, whether you have HIV-related medical conditions, and how closely you have followed (adhered to) your treatment. Talk with your doctor if you are concerned about the results of your viral load tests.

How often should I have a CD4 count?

CD4 counts also indicate how well your treatment regimen is working. Your CD4 count should be tested every 3 to 6 months throughout your treatment. HIV treatment should increase your CD4 count or at least keep it from going down. Talk to your doctor if you are concerned about your CD4 counts.

My doctor wants to change my treatment regimen. Why?

There are several reasons why you may need to change your treatment regimen. **Two of the most important reasons are *drug toxicity* and *regimen failure*.**

Drug toxicity means that your treatment regimen creates side effects that make it difficult for you to take the drugs.

Regimen failure means that the drugs are not working well enough.

Ask your doctor to explain why you need to change your treatment. If the reason is drug toxicity, your doctor may change one or more of the drugs in your regimen. If the reason is regimen failure, your doctor should change all of your drugs to medications that you have never taken before. If you have been taking three drugs and all three drugs cannot be changed, at least two drugs should be changed. Using new drugs will reduce the risk of drug resistance.

Terms Used in This Chapter

Adherence: how closely you follow, or adhere to, your treatment regimen. This includes taking the correct dose at the correct time as prescribed by your doctor.

Baseline: an initial measurement (such as CD4 count or viral load) made before starting therapy and used as a reference point to monitor your HIV infection.

Drug Resistance: HIV can mutate (change form) while a person is taking anti-HIV medication. This may result in HIV that cannot be controlled with certain medications.

HIV Treatment Regimen Failure

What is regimen failure?

Regimen failure occurs when the anti-HIV medications you are taking do not adequately control the infection. Factors that may cause regimen failure include:

- Poor health before starting the treatment regimen
- Poor adherence to the regimen (not taking medications exactly as instructed by your doctor, including missed doses)
- Previous anti-HIV treatment and/or drug resistance
- Alcohol or drug abuse
- Medication side effects, medication toxicity, or interactions with other medications
- Medication poorly absorbed by the body
- Medical conditions or illnesses other than HIV infection

How is treatment regimen failure identified?

In settings where the viral load and resistance for HIV testing are widely available and routinely used for monitoring people on ARV treatment, increase on the viral load is usually the first indicator of viral resistance and hence treatment failure. For resource-poor settings like Kenya, progression of HIV infection to AIDS after a period of good response to the ARV treatment coupled with decline of CD4 count of more than 30% in six months while on ARVs is an indication of treatment failure. Also treatment failure has occurred if you experience an HIV-related infection or a decline in physical health despite at least 3 months of anti-HIV treatment.

What happens if my regimen fails?

If your treatment regimen fails, your doctor will evaluate your treatment history, medication side effects, problems you may have

had with taking the medications as directed, your physical condition, and results of drug resistance testing to determine why your regimen is failing. You and your doctor may then select a new drug regimen to better control your infection.

Terms Used in This Chapter

Baseline measurement: An initial measurement (such as CD4 count or viral load) made before starting therapy and used as a reference point to monitor your HIV infection.

Viral load: the amount of HIV in a sample blood.

Toxicity: *the harm a medication can do to your body.*

Regimen failure: this is when the anti-HIV medications you are taking do not adequately control the infection.

Changing My HIV Treatment Regimen

How will my doctor and I know what medications to use next?

Before changing your treatment regimen, your doctor will try to find out why your current regimen is not working. Your doctor will evaluate your *adherence* to the regimen, the regimen's *tolerability*, and *medication interactions*. Whether you and your doctor decide to change your regimen and what new medications you will take will depend on why your current regimen is failing.

What is adherence?

Adherence refers to how closely you follow (adhere to) your treatment regimen. If your regimen is failing because you cannot adhere to it, you and your doctor should discuss why you are having difficulty taking your medication and what you can do to improve your adherence. Your doctor may change your regimen to reduce the number of pills you take or how often you take them. (For more information see Chapter 7)

What is tolerability?

Tolerability refers to how many and what types of negative medication side effects you experience. If the side effects are severe, you may need to change your regimen. Your doctor will ask you what side effects you have and how long you have had them. You and your doctor will decide whether to treat the side effects or to change your anti-HIV medications.

What are medication interactions?

There are some drugs which when taken concurrently with anti-HIV medications have drug interaction that result in ineffectiveness either of the anti-HIV medication or the other drug. Anti-HIV medications may interact with other medications you are taking.

This may reduce the effectiveness of the medications or increase the risk of negative side effects. You and your doctor should review all of your medications, including over-the-counter medications and herbal remedies. You should also review whether your medications should be taken with food or on an empty stomach.

Changing Regimens

If your regimen is failing and you and your doctor have ruled out adherence, tolerability, and medication interactions, you should consider changing your regimen. Before changing anti-HIV medications, talk with your doctor about:

- anti-HIV medications you have taken before
- the strength of the new medications your doctor recommends
- possible side effects of the new medications
- how well you will be able to adhere to the new regimen
- the number of anti-HIV medications that you have not yet used

Your doctor will confirm that your regimen is failing with at least two viral load tests and three CD4 count counts. You should also be tested for drug resistance *while you are taking the failing regimen*.

In general, your new treatment regimen should include three or more medications. You and your doctor will choose the medications based on your medication history, results of resistance testing, and medication side effects.

Terms Used in This Chapter

Treatment tolerability: refers to how many and what types of negative medication side effects you experience

Drug interaction: This refers to when some drugs which when taken concurrently with anti-HIV medications result in ineffectiveness either of the anti-HIV medication or the other drug

Viral load: the amount of HIV in a sample blood.

What is Treatment Adherence?

What is adherence?

Adherence refers to how closely you follow a prescribed treatment regimen. It includes your willingness to start treatment and your ability to take medications exactly as directed.

Is adherence important for HIV treatment?

Yes! Adherence is a major issue in HIV treatment for two reasons:

- Adherence affects how well anti-HIV medications decrease your viral load. When you skip a medication dose, even just once, the virus has the opportunity to reproduce more rapidly. Keeping HIV replication at a minimum is essential for preventing AIDS-related illnesses.
- Adherence to HIV treatment helps prevent drug resistance. When you skip doses, you may develop strains of HIV that are resistant to the drugs you are taking and even to drugs you have not yet taken. This may leave you with fewer treatment options should you need to change treatment regimens in the future. Because drug-resistant strains can be transmitted to others, engaging in risky behavior can have especially serious consequences.

Although there are many different anti-HIV medications and treatment regimens, studies show that *your first regimen has the best chance for long-term success*. Taking your drugs correctly (adherence) increases your odds of success.

Why is adherence difficult for many people with HIV?

HIV treatment regimens can be complicated; most regimens involve taking multiple pills each day. Some anti-HIV medications must be taken on an empty stomach, while others must be taken

with meals. This can be difficult for many people, especially for those who are sick or are experiencing HIV symptoms or negative drug side effects.

Other factors that can make it difficult to adhere to an HIV treatment regimen include:

- Experiencing unpleasant medication side effects (such as nausea)
- Sleeping through doses
- Travelling away from home
- Being too busy
- Feeling sick or depressed
- Forgetting to take medications
- Lack of support from the family and the community

What can I do to adhere to my treatment regimen?

There are many things you can do to better adhere to your treatment regimen. One of the most important things you can do when starting a treatment regimen is to talk with your doctor about your lifestyle. He or she will then be able to prescribe a regimen that works best for you. Topics you should address with your doctor include:

- Your travel, sleep, and eating schedule
- Possible side effects of medication
- Other medications you are taking and their possible interaction with anti-HIV medications
- Your level of commitment to following an HIV treatment regimen

Many people adhere well to their treatment early on, but find adherence becomes more difficult over time. Talk with your doctor about adherence during every visit. Your commitment to a treatment plan is critical; studies show that *patients who take their medications correctly achieve the best results*.

Adhering To My HIV Treatment Regimen

What should I do before I begin treatment?

Before you begin an HIV treatment regimen, there are several steps you can take to help you with adherence:

- Talk with your doctor about your treatment regimen.
- Get a written copy of your treatment plan that lists each medication, when and how much to take, and if it must be taken with food or on an empty stomach.
- Understand how important adherence is
- Be honest about personal issues that may affect your adherence. Adherence may be harder for people dealing with substance abuse or alcoholism, unstable housing, mental illness, or other life challenges.
- Consider a “dry run” Practice your treatment regimen using vitamins, jelly beans, or mints. This will help you determine ahead of time which doses might be difficult to take correctly.
- Develop a plan that works for you.

Many people find it helpful to identify the activities they normally do at the times they will be taking their medication. People who arrange their medication schedule around their daily routines adhere to their treatment plans better than those who do not.

How can I maintain adherence after I start treatment?

- Take your medication at the same time each day.
- Put a week’s worth of medication in a pill box at the beginning of each week.
- Use timers, alarm clocks to remind you when to take your medication.
- Keep your medication in the place where you will take it. You may want to keep backup supplies of your medication at your workplace or in your purse.
- Keep a medication diary. Write the names of your drugs in your daily schedule, then check off each dose as you take it.
- Plan ahead for weekends, holidays, and changes in routine.
- Develop a support network of family members, friends, or coworkers who can remind you to take your medication. Some people also find it helpful to join a support group for people living with HIV infection.

- Monitor your medication supply. Contact your doctor or clinic if your supply will not last until your next visit.

What should I do if I have problems adhering to my treatment regimen?

It is important that you tell your doctor right away about any problems you are having with your treatment plan. Talk with your doctor about other treatment options. Your doctor needs to stay informed to help you get the most out of your treatment regimen and to provide workable treatment options.

Terms Used in This Chapter

Adherence: how closely you follow, or adhere to, your treatment regimen. This includes taking the correct dose at the correct time as prescribed by your doctor.

HIV and Pregnancy

I am HIV positive and pregnant. Should I take anti-HIV medications?

You should take anti-HIV medications if:

- you are experiencing severe symptoms of HIV or have been diagnosed with AIDS
- your CD4 count is 200 cells/mm³ or less
- your viral load is greater than 1,000 copies/mL

You should also take anti-HIV medications to prevent your baby from becoming infected with HIV. Specific treatment to prevent mother-to-child transmission of HIV is discussed below.

What medications should I take if I am pregnant or think I might become pregnant?

If you are pregnant or may become pregnant, you should consider the risks and benefits of HIV treatment to both you and your child. Some medications (such as Sustiva) should be avoided because they may cause birth defects if taken early in pregnancy. The effects of other anti-HIV medications are not yet known. It is important for you to talk with your doctor before and during your pregnancy so that together you can decide on the best treatment for you and your baby.

In Kenya currently, to reduce the risk of passing HIV to the un-born baby, a single dose of antiretroviral drug Nevirapine (NVP) given to an HIV infected woman in labour and another to her baby within 3 days (72hours) of birth. This reduces the transmission rate from the mother to the baby significantly.

This treatment may also be given as a three-part ZDV (also known as zidovudine, AZT, or Retrovir) regimen. This has not been widely availed in Kenya however it is in the process of introduction.

What is the three-part ZDV regimen?

1. A HIV infected pregnant woman should take ZDV starting at 14 to 34 weeks of pregnancy. You can take either 100 mg five times a day, 200 mg three times a day, or 300 mg twice a day.
2. During labor and delivery, you should receive ZDV intravenously (through an IV in the vein).
3. Your baby should take ZDV (in liquid form) every 6 hours for 6 weeks after he or she is born.

I am already on an HIV treatment regimen. Do I need to change my medications?

If you are already taking anti-HIV medications, talk with your doctor about the potential risks and benefits to your baby if you decide to continue your treatment regimen during your pregnancy. You and your doctor may decide to change your medications or change your medication dose. Make sure that your regimen includes the appropriate dose of ZDV.

In general, efavirenz (Sustiva), stavudine (Zerit), hydroxyurea, and the oral liquid form of amprenavir (Agenerase) should not be used during pregnancy.

Will my baby be born HIV infected?

No one can tell you for sure if your baby will be born HIV infected. The treatment regimen has been shown to reduce the risk of passing HIV to your baby by almost 70%. Additional anti-HIV medications can treat your infection and may provide extra protection for your baby. However, the possible problems with using multiple medications during pregnancy are not well understood.

I am HIV positive and don't want to infect others. What should I do?

Understanding how HIV is transmitted is an important step in prevention. Talk with your doctor or counselor about how HIV is transmitted and what you can do to prevent infecting others. Each time you visit your doctor, discuss your high-risk behaviors, such as unprotected sex and needle sharing.

You may feel reluctant to talk about your high-risk behaviors. It can be difficult to change behaviors, even when you want to. However, it is important to be honest with your doctor or counsellor about risky activities. You and your doctor can then discuss ways to minimize the risk of infecting others.

If you are a woman, you and your doctor should discuss ways to prevent pregnancy. If you want to become pregnant, you and your doctor can talk about what you should do to prevent transmitting HIV to your baby.

How can I prevent infecting someone else?

Successful HIV treatment can lower your viral load, which may reduce the risk of HIV transmission. But there are other factors that influence sexual transmission of HIV, such as:

- presence of other sexually transmitted diseases (STDs)
- genital irritation
- menstruation
- taking birth control pills
- hormone imbalances
- vitamin and mineral deficiencies

Always use prevention strategies, such as condoms and safer sex practices. If you inject drugs, don't share your needles with anyone else. Talk with your doctor if you have trouble sticking to these prevention strategies. You and your doctor can then find ways to make your high-risk behaviors safer.

Should I tell my partners that I am HIV infected?

Yes. It is very important that you tell your sexual partners and people with whom you have shared injected drugs that they may have been exposed to HIV and should be tested. You and your doctor or counsellor can discuss the best way to notify your partners.

I am taking anti-HIV medications and my viral load is undetectable. Am I cured? Can I infect others?

An undetectable viral load does not mean that you are cured. It means that the amount of HIV virus in your blood is so low that the viral load tests cannot detect it. You are still infected with HIV and can infect others. You should continue to use prevention strategies and should see your doctor regularly.

It is important to use HIV prevention strategies even if your partner is also HIV infected. Your partner may have a different strain of the virus that could act differently in your body or be resistant to different anti-HIV medications.

What about treatment of opportunistic infections?

Once you have tested HIV positive, you need to seek treatment for any infections that may occur. This ensures that such infections do not progress to become chronic and you can lead a healthier life. It is important to avoid purchasing over the counter drugs even for simple illnesses as these drugs may interact with the ARVs that you are taking.

HIV&AIDS and Alternative Therapies

What is Alternative Medicine?

The terms “alternative,” “complementary,” or “unconventional” therapy cover a broad range of healing philosophies and approaches. Some approaches are consistent with physiological principles of Western medicine, while others constitute independent healing systems. Some therapies are so far outside the realm of accepted medical theory and practice that they are difficult to subject to standard evaluative techniques.

How Does Alternative Medicine Fit Into the Treatment of HIV Disease?

At the beginning of the epidemic, little or no treatment was available for people with HIV/AIDS. Although as yet there is no cure, over the last decade researchers have identified a number of drugs that slow progression of the virus as well as therapies to treat the many opportunistic infections that attack people with HIV disease. The key to effective treatment is early detection and intervention. Some early treatments aim to strengthen the immune system, help patients reduce stress, and maintain good nutritional practices and appropriate exercise regimens. Many of the alternative therapies described below place significant emphasis on these lifestyle issues. Taking an active role in any disease is an important addition to treatment. Consideration of alternative therapies in conjunction with conventional medicine may offer additional opportunities for persons living with HIV/AIDS to be proactively involved in their treatment.

How to Approach Alternative Therapies

Here are a few suggestions to follow before getting involved in any alternative therapy.

- Obtain objective information about the therapy. Besides talking with the person promoting the approach, speak with people who have gone through the treatment — preferably both those who were treated recently and those treated in the past. Ask about the advantages and disadvantages, risks, side effects, costs, results they experienced, and over what time span results can be expected.
- Inquire about the training and expertise of the person administering the treatment (i.e., certification). If any uncertainty remains, verify the information.
- Consider the costs. Alternative treatments may not currently be reimbursable by health insurance.
- Discuss all treatments with your primary care provider, who needs this information in order to have a complete picture of your treatment plan.

People with HIV/AIDS use many kinds of alternative approaches to treatment. Some of the most common are briefly described below.

Herbal Medicine

The use of plants as medicine is common to many cultures, and a number of advanced pharmaceutical drugs were derived from plants. Not just herbalists but naturopaths, homeopathic, Ayurvedic and Chinese herbal medicine practitioners all use herbs as one component in an overall system of medicine. Herbs have been used extensively in hopes of improving immune response and reducing symptoms. Aloe vera, St. Johnswort, echinacea, licorice, and ginseng are just a few of the herbs used to treat HIV/AIDS.

Homeopathy

Homeopathic medicines, which include minerals, vitamins, and animal products, are natural substances given in very low doses. Homeopathy is based on the principle that “like cures like,” that is, substances that in large doses would cause adverse symptoms will, in small doses, treat those same symptoms. Homeopathy is highly individualized to a patient’s symptoms.

Acupuncture

Acupuncture involves the relatively painless insertion of extremely thin needles into the skin at specific points to help balance the body’s flow of energy, referred to as qi (“chee”). When needles are inserted into the appropriate points, it is thought that

energy is unblocked, and symptoms can be relieved. Variations of acupuncture include acupressure and shiatsu (pressure and massage of acupuncture points). Acupuncture is sometimes used to relieve some HIV-related symptoms such as neuropathy, fatigue, and pain. It is also used in an attempt to strengthen the immune system.

Body Work and Massage

Massage is the manipulation of tissues (as by rubbing, stroking, kneading, or tapping) with the hand or an instrument-for remedial or hygienic purposes. Therapeutic massage is not only beneficial in relieving a variety of physical symptoms including chronic pain, but it may also be effective for relaxation and stress reduction. Massage can help people with HIV/AIDS relieve chronic muscle tension and ease the mental and emotional stress that accompany the illness. Body manipulation/massage techniques that are being used to treat HIV/AIDS include acupressure, the Alexander technique, deep muscle therapy, polarity therapy, Reiki, Rolfing, Shiatsu, Rubenfeld Synergy, Swedish massage, and therapeutic massage.


Chiropractic medicine is a system of therapeutics that attempts to restore normal function by manipulation and treatment of the body structures, especially those of the vertebral column. Through manipulation, chiropractors may be able to relieve joint stiffness and pain, which are common complaints of HIV/AIDS patients.

Yoga is the practice of an ancient system of breathing exercises, postures, stretching exercises, and meditations based on Ayurvedic medicine and Indian philosophy and religion. The aim of Yoga is to help the individual balance the body's energy centers (chakras). Its practitioners believe that yoga can aid in detoxification, strengthen particular organs, improve stamina, and alleviate chronic fatigue.

Mind-body Therapies

Sometimes called psychoneuroimmunology (PNI), these approaches are based on the concept that the mind or brain can influence the body's ability to fight disease.

Meditation uses deep breathing or other focusing techniques to enable a person to center his or her thoughts. Meditation may be used to reduce tension, fatigue, or anxiety and increase resistance to stress.



Visualization is the process by which a person is directed to see himself or herself in some other physical, emotional, or spiritual state. Patients might be guided to imagine themselves in a state of vibrant health and the disease organisms as weak and destructible. Through these mental images, patients might try to direct their immune systems to fight the virus. Other mind-body techniques for people with HIV/AIDS include hypnosis, humor therapy, biofeedback training, and listening to inspirational or relaxational audiotapes.

Nutrition and AIDS

People infected with HIV have greater nutritional needs and adequate diets are essential to promoting a strong immune system, to prevent wasting, and to have a good quality of life. Inadequate nutrition increases susceptibility to opportunistic infections and a more rapid HIV disease progression. To keep track of your nutritional status you need to:

- Monitor your weight. How do your clothes fit? Any unintentional weight loss is a red flag.
- Monitor your body shape. Are you losing definition or muscle mass?
- Are you eating enough nutritious food? A major cause of wasting is inadequate nutritional intake (not eating enough)
- Get help right away for problems with nutrition such as loss of appetite, diarrhea, nausea/vomiting, and taste changes

Eating Well

The nutrients needed for life are calories, proteins, carbohydrates, fats, fluids, vitamins and minerals. Nutritional needs vary from person to person. For specific nutrition information discussion with your health care worker or nutritionist. However, to stay healthy, make a commitment to have the best nutrition you can.

Nutrients in Food

Calories:

Getting enough calories is the number one priority for energy (fuel), to fight infections, to maintain the normal body mass. If you are losing weight, you are not getting enough calories. Carbohydrates (starches and sugars) and fats provide most of our calories.

Protein:

Protein provides building blocks for new cells, including muscles and immune cells and repair and maintenance of the body tissues. If you are not getting enough calories, the protein you eat, and the protein in your body will be broken down for fuel. Your protein needs are higher than normal with HIV.

Fats and Oils:

Fat is an important source of essential fatty acids for healthy cells.

- The vitamins A, D, E and K are found in fats and oils contained in foods like liver, nuts, seeds, milk, and butter and egg yolk.
- Fats provide concentrated calories in foods like milk, cheese, meats and peanuts.

A high fat intake is not a good idea because it can cause digestive problems, diarrhea, and malabsorption. Some fat in your diet is necessary, but try to aim for a moderate amount.

Water:

Water is essential for every cell in our body to function properly. Drink at least 1.5 liters of water daily. If you are losing water through sweats, diarrhea or vomiting increase your fluid intake.

Vitamins and Minerals:

Vitamins and minerals are important in helping the chemical reactions of the body, repair, heal cells and replenish nutrients lost through various processes including medications. They do not provide calories or protein, and cannot replace food. Deficiencies are common even with a good diet, but as HIV infection increases the need for vitamins and minerals, supplements are recommended for all HIV-positive people. However you need to discuss this with your doctor. Deficiencies in vitamin A, B complex and C have been associated with rapid progression of HIV disease.

With minerals:

- Calcium is essential for skeletal development (bones) and firmness
- Iron is required for oxygen exchange in the blood and is critical for prevention of anaemia

- Selenium and Zinc are essential for immune functioning and their deficiency has been associated with rapid progression to AIDS.

Foods

Cereals and Grains:

Cereals and grains are inexpensive and easy to digest. They contain B vitamins, fiber and also carbohydrates, which produce calories and energy. These foods should make up the main part of your diet. Try to have one or two servings at each meal and snack

Fruits and Vegetables:

Fruits and vegetables boost immunity and provide vitamins, carbohydrates and fiber. Choose foods that have a lot of colour e.g. red, dark green, orange. Try to buy and eat fresh fruit and vegetables every day. Fruits are good substitute for sweets.

Milk Products:

Milk products are loaded with protein, vitamin and minerals. Including milk and other dairy products in your diet helps you meet your protein requirements. You should try to have some milk and or milk based foods each day such as: yogurt, cheese, cottage cheese, milkshakes, and puddings.

If you are lactose intolerant, it does not mean that you have to give up milk. Try aged cheese, yogurt or goat and sheep milk and milk products. Many lactose intolerant people have no difficulties with these.

Meat and Alternatives:

You should eat from this food group at least twice a day. It includes meat, fish, eggs, legumes (dried peas/beans), and peanuts but you should avoid red meat. White meat and alternatives are the best sources of protein and a good source of many minerals.

Foods that you need to avoid

There are certain foods and consumables that you should be avoided by people living with HIV and AIDS. For example:

- i) Although sugar adds flavor and calories to foods you should avoid it. Therefore, if you want to eat something sweet, try fresh or dried fruits.
- ii) Alcohol weakens the immune system, and can contribute to malnutrition and liver disease. It should therefore be avoided altogether.

Other foods that should be avoided include:

- Soda (Coca Cola, Fanta etc)
- Too Much pepper
- Cigarettes
- Canned foods
- Fatty foods e.g chips
- Deep fried foods

If You Are Having Trouble Eating:

- Eat small frequent meals and snacks 5-6 times per day for easier digestion and to make sure you are getting enough to eat. If you usually eat once or twice a day increase by one meal at a time.
- Create an eating schedule much the same as a medication schedule
- You can also seek help from your doctor/health care worker

It is important to work with your doctor or health care worker to design diets that provide those nutrients that may be lacking. Some health care workers use common approaches to nutrition, while others have unique approaches.

In General

- Make every bite count. Choose nutritious, nutrient-dense foods such as: fish, poultry, nuts, beans, peas, pumpkins, green leafy vegetables and fruits.
- Restrict your foods as little as possible because it makes it harder to meet your nutritional needs
- Exercise to maintain muscle mass and prevent wasting. Exercise to the level you can tolerate without becoming exhausted. Consult your doctor before starting a new exercise program.
- Keep food and preparation areas clean and fresh.

- Wash hands thoroughly before preparing food
- Do not eat raw or undercooked eggs or meat
- Do not eat expired foods, fresh foods are best
- Drinking water should be boiled to eliminate chances of disease.

Making sure your food is safe is extremely important when you have a weakened immune system. Food poisoning can occur from eating contaminated food or water, or from unsafe food handling.

Dietary Supplements

Dietary supplements are commonly used in an effort to boost the immune system. Foods or substances derived from foods (garlic, Chinese bitter melon, turmeric) are also used, as well as nonfood dietary supplements such as shark cartilage or blue-green algae (spirulina). Vitamins, minerals, and amino acids are also used in an attempt to boost the immune system. Before using dietary supplements it is important to discuss them with your doctor and health care worker or nutritionist.