aids law unit

TREATMENT FOR HIV/AIDS: a Guide

A publication of the AIDS Law Unit,
Legal Assistance Centre

INTRODUCTION

Although there is currently no cure for HIV/AIDS, treatment has been developed which can stop the progression of the disease. This booklet looks at some of the questions that you may have about treatment, where you can go and what you have to do to get treatment if you or someone you know needs it.

- Getting as much information as possible before you start treatment is very important. It will help you make informed decisions about your treatment.
- Information about HIV treatment changes very quickly, so only rely on information, whether printed or from the internet, that is clearly dated and that is up to date.
- If you are learning about HIV for the first time, then discuss any question you may have with your doctors or healthcare workers.
- Information in this booklet is not intended to replace information from your doctor or other healthcare workers. Decisions relating to your treatment should always be taken in consultation with your doctor.
- Before you start with this booklet, it is important that you under stand certain words and concepts that relate to treatment for HIV.

1. What is HIV, and what is AIDS?

HIV is short for the Human Immuno-deficiency Virus. HIV is a virus that is only found in human beings. It attacks and slowly damages the body's immune system (the body's defence against infections and diseases). One can become infected with HIV through contact with infected blood, through unprotected sexual intercourse, through infected breastmilk, or intraveneous drug use (IDU).

HIV causes AIDS. Over time HIV severely damages a person's immune system, so that the body can no longer fight off infections and other diseases. When this happens, you get a group of particular medical conditions called 'AIDS-defining conditions or illnesses'' and we say that you have developed Acquired Immune Deficiency Syndrome (AIDS).

1.1 What is the immune system?

The immune system is your body's defence against disease. We measure the state of your immune system with a test that tells us how many CD4 cells are in your blood. This is called the CD4 test. (see 1.3 below)

1.2 What are opportunistic infections?

HIV itself is not usually the cause of death in an infected person. Instead, it weakens the body's ability to fight disease. If HIV is not treated, these infections will eventually increase in number, and will eventually be fatal. Infections which are rarely seen in those with normal immune systems are deadly to people living with HIV.
People with HIV can get many infections (called opportunistic infections, or OIs). **Some examples of OI's are given below, at 11.** Many of these illnesses are very serious, and they need to be treated. Some can be prevented.

1.3 The CD4 test

The test that measures how strong your immune system is, and how much damage has been cause by HIV, is called a CD4 or T4 test.
Within a few weeks of infection with HIV, your CD4 count falls and then recovers. It then falls again more slowly (usually over several years). A count of 200 is currently used as a guide to start treatment.

Your CD4 count should rise again above 200 if your treatment is working.

Even though it is important for general monitoring, this test is mainly used to decide when you need to start treatment. If you have any HIV-related illnesses then you may need treatment even at a higher CD4 count.
If you do not have access to regular CD4 tests, you can still benefit from treatment.

Even if you start with a very low CD4 count below 50, you could regain enough of your own immune system for your body to recover from many HIV-related illnesses.
If you use HIV treatment at the right time, and in the right way, you should stay healthy for a long time.

1.4 What does "viral load" mean?

Your viral load is a measurement of the number of particles of the virus in your bloodstream. It is measured in copies per milliliter of blood (copies/mL).

A viral load test measures how much HIV is in a sample of blood. If you have a high viral load it means that there are many copies of HIV in your bloodstream.
After infection, viral load levels are very high (over 1 million), and then over the first six months or so, your body fights back and brings your viral load down to much lower levels. Over time, though, the levels of the virus increase again, and it is usually very high (over 100,000) by the time that your CD4 count reaches 200.
The viral load test is used after you start treatment to check that the drugs are working. If your viral load is brought down to less than 50 copies/mL then treatment is working, and you can stay healthy for many years.

1.5 What is "drug resistance"?

Resistance refers to the ability of some types of virus, including HIV, to change or adapt in such a way that the drugs used to treat them are no longer effective. The main cause of resistance is the failure of people living with HIV to take their drugs as prescribed i.e. as instructed by your healthcare worker ("adherence"). It is for this reason that we stress the importance of adherence for people taking ARV's.
Now that you are familiar with these terms, we can start talking about treatment for HIV.

2. What is HAART?

Because HIV belongs to a group of viruses called ***retroviruses,*** treatment to fight HIV infection is known as ***antiretroviral therapy (ART)***.

Because we have learned that the best way to treat HIV effectively is with a combination of three antiretroviral drugs (ARV's), this multiple-medication approach is often referred to as ***HAART***, which stands for ***Highly Active Antiretroviral Therapy, combination therapy, or triple therapy. All these names refer to the same thing. For the purposes of this pamphlet we will use the term "ARV", or refer simply to treatment.***

3. Does it work?

Yes! In every country where treatment is available, AIDS-related deaths and illnesses drop dramatically. For those who are fortunate enough to have access to treatment, HIV has become manageable disease, instead of a death sentence.
Treatment works for women, men and children. It works no matter how you were infected with HIV, whether this was sexually, through intravaneous drug use (IDU), or through contact with infected blood.
Taking ARV's, exactly as prescribed, will reduce the virus in your body to tiny amounts. This then lets your immune system recover and get stronger by itself.

4. How long will the drugs work?

Now that there are treatments for HIV it is important for you to know your HIV status so that you can benefit from treatment if you need it.
Treatment for HIV using three different ARVs has now been used in some countries for over eight years.
The length of time that any combination of ARVs will work depends mainly on you not developing resistance. This depends on getting, and keeping, your viral load to undetectable levels, below 50 copies/mL.
If your viral load stays undetectable, you can use the same combination for years.

HIV uses CD4 cells as factories to make hundreds of copies of itself. Diffferent drugs work at different stages ofthe HIV life cycle.

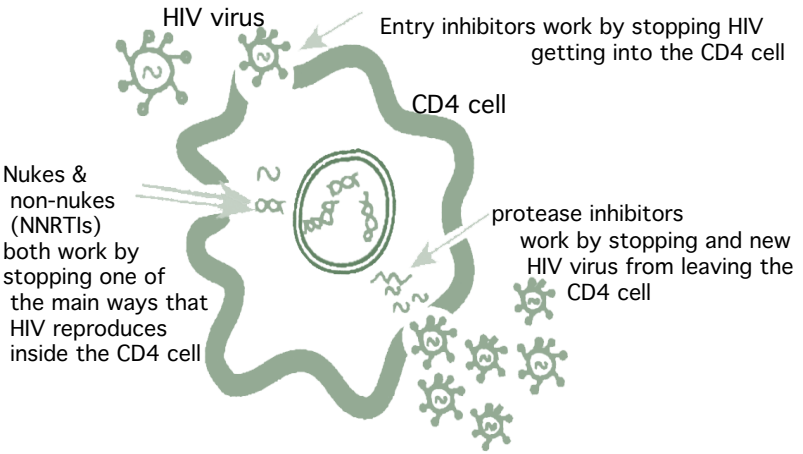

Fig1: HIV drugs work in different ways

5. Does everyone who is HIV positive need treatment?

- About one third of HIV-positive people will stay well for up to 10 years after infection, even without treatment.
- About 60% will need to start treatment after4 - 5 years.
- 2-3% of people become ill more quickly and need treatment much earlier.
- 2-3% can go for 15 - 20 years without treatment.

At some point, nearly all HIV-positive people will need treatment. The point at which people will require treatment differs from person to person because HIV infection progresses in different people at very different rates.

Not everyone who is diagnosed as being HIV positive will need treatment immediately. You can maintain your health, even if you are infected, for a long time by following proper nutrition, avoiding habits like smoking or drinking alcohol, and living positively. Ask you doctor about nutrition and living positively.

Sooner or later, however, everyone who is infected will require ARV's to continue staying healthy.

Because treatment is long term, and because the ARV's are extremely powerful, it is important that people should only go on treatment when it is necessary for them to do so. This decision must be made in consultation with your doctor.

Whether you need treatment is something you have to discuss with your doctor.

6. When do I have to start treatment?

The Treatment Guidelines developed by the Ministry of Health and Social services says that patients should go on treatment when their CD4 cell count is below 200.

It is recommended that you_start treatment when you CD4 count is around 200.

Before going on treatment:

- Ask your doctor to tell you about the different ARVs that you can use. You need to know the good and bad things about each of them.
- Take time to think about what you want to do. Do not feel rushed or pressured into doing something you don't understand. If you have only recently been diagnosed HIV-positive, you will need to deal with that first.

While your CD4 count is above 300, you still have a good immune system. Below 300 you are at a higher risk of infections that cause diarrhoea and weight loss.

If your CD4 count falls below 200, your risk of developing a pneumonia called PCP increases. If it falls below 100, then your risk of serious illnesses increases even further.

A low CD4 count does not mean that you will definitely become ill. It is, however, much more likely. Most of the drugs used to treat these HIV-related illnesses can be more toxic and difficult to take than regular ARV's
Although you may be worried about using treatments, HIV and AIDS is a very real and life-threatening illness. Illnesses that can occur at any time when your CD4 count is below 200 can be fatal.

7. What about treatment in pregnancy?

Women with HIV can be effectively treated during pregnancy.
Using ARV's during pregnancy can improve the (be better for the) mother's health and also dramatically reduces the risk of HIV being passed to the baby. Currently, Namibia uses a single dose of the drug Nevirapine, given to the mother when she goes into labour, and a single dose given to the baby soon after childbirth to_reduce the risk of transmission of HIV from an infected mother to her baby.

8. How do children use HIV treatment?

The principles for treating children with HIV are very similar to those for treating adults. However, there are some important differences.
The immune system can be different in babies, toddlers, infants, children,adults. This is why specialist HIV care, where it is available, is recommended at all ages.

9. Is treatment the same for people who have HIV and TB or malaria?

TB (and malaria) can be harder to treat if you also have HIV. They can also make HIV progress more quickly. It is very common for people to have TB or malaria as well as HIV and it is important for your doctor to know about this. HIV treatment is recommended for anyone who also has active TB infection, even if the CD4 count is higher than 200. Different ARVs are recommended if you also need to take treatment for TB.

10. Late HIV diagnosis and low CD4s

Some people, from all age ranges, only find out that they are HIV-positive when they become ill and are admitted to hospital. This often means starting treatment straight away, especially when the CD4 count is below 100.
For people who only discover that they are HIV-positive when their CD4 count is very low, there is still very good news.
Even with a very low CD4 count of, for example, below 10, if you follow your treatment very carefully, you have a very good chance that the treatment will work. Your viral load will drop and your CD4 count will rise again to safer levels. This is not a reason to delay treatment, however, because your chances of the treatment working are much better if you start with treatment before your immune system is too weak.

11. Besides a CD4 test, how else can I know whether I need treatment?

If you have any of the medical conditions set out below, you may already need treatment, and you should consult with your doctor to find out whether you need to go on treatment.. If you find any of these names for symptoms too difficult, or confusing, don't be too concerned. The important thing is that you are able to identify the symptoms that indicate that you may need to go on treatment. These are only some of the symptoms that may indicate that you need to go on treatment. If you are HIV positive, you should monitor your health carefully, and ask you doctor about any strange symptoms that you are experiencing.

If you don't know your HIV status, have yourself tested!

HIV Wasting Syndrome

If you have lost a lot of body weight and this is accompanied by symptoms of diarrhea, fever or weakness that persist for over a month, you may have HIV wasting syndrome

Pneumocystis Carinii Pneumonia (PCP)

This is the most common HIV/AIDS related condition, occurring in about 85% of people with HIV. It is caused by a fungus that infects the lungs and causes a pneumonia-like condition.

If you have difficulty breathing, fever, and a dry cough, you should consult a doctor immediately

Toxoplasmosis of the Brain ('Toxo')

In people whose immune systems have been weakened by HIV/AIDS, symptoms of toxoplasmosis are often brain-related and severe. These symptoms can include:

- Disturbances in mental functions, especially disorientation, difficulty concentrating or behavioral changes
- Fever
- Headache
- Seizures
- Disturbances in nerve function, especially abnormal movements, diffi culty walking, difficulty speaking and partial loss of vision

If toxoplasmosis affects the eyes of a person with a weakened immune system, there may be blurred vision, "spots" in the field of vision, eye pain and extreme sensitivity to light.
If toxoplasmosis affects the lungs, there can be shortness of breath, fever, a dry cough, coughing up of blood and, eventually, respiratory failure

Cryptosporidiosis with diarrhea ('Crypto')

Symptoms of cryptosporidiosis include abdominal (stomach) cramping, especially in the right side, nausea, and diarrhea lasting up to 21 days. For people with HIV, this is dangerous because diarrhea and vomiting causes dehydration.

12. Adherence – and why it is important

12.1 What is adherence?

Adherence is a word to describe taking your ARVs exactly as instructed by your health care worker. This includes taking them at the right time as well as following any special diet restrictions.
The reason this is so important is because ARVs will only work if you keep a constant minimum level of each ARV in your body all the time. If it drops below this minimum level then your virus can develop resistance to the ARVs, and the ARVs will stop working.

ARVs are a bit like TB drugs – you need to take all of them at the right time and continue to take them, even if you feel better.
It is important that you develop a routine - even if you only have to take one pill twice a day. You may need some support to get used to the changes it makes in your life. Adherence can be very difficult.

Adherence rates	% of people undetectable
over 95%	81%
90-95%	64%
80-90%	50%
70-80%	25%
Under 70%	6%

Adherence is the most important thing you have to think about when you start taking ARVs.
Start treatment when you can give yourself the extra time and space you may need to adjust.
During the first few weeks, nothing else should take priority over getting your treatment right.

Diet restrictions are very important. Ignoring these can be like only taking half a dose. You will not absorb enough of the ARV for it to work properly. Resistance is then more likely to occur which means you will not be able to use these ARVs in the future.
If you find a way to take all your ARVs as you are supposed to, you will get good results.

- Be strict with yourself in assessing how successful you are in taking the ARVs at the right time, and in the right amounts, during a regular week.
- If it's not looking so good, you need more support.
- Talk to your doctor!

Tips to help...

- Get all the information on what you will need to do be fore you start treatment: How many tablets? How big are they? How often do you need to take them? How exact do you have to be with timing?
- Are there food or storage restrictions?
- Are there other choices?
- Use the daily chart in this leaflet to plan your timeta ble and use it to get used to the routine. For the first few weeks mark off each dose and the time that you took it.
- Make sure that you tell your hospital or clinic if you have difficulties with side effects.
- Divide up your ARVS each morning or each week if you use a pill box. Then you can always check if you think you have missed a dose.
- Use an alarm clock. Use it for both morning and evening doses.
- Take extra ARVs with you if you go away for a few days.
- Keep a small supply where you may need them in an emergency. This can be in a cool place at work or at a friend's house.
- Get friends to help you re member difficult dose times. Ask them to remind you when you are out socially.
- Ask friends who are already on treatment what they do. Ask them how well they are managing.
- Ask your doctor for a sup- ply of medications to con- trol nausea and diarrhoea. These side effects are the most common when start- ing therapy.
- Most combinations are twice-daily regimens. This usually means taking them every 12 hours. However, several ARVs only need to be taken once a day. This usually means taking them every 24 hours.
- Completely missing a once- daily dose may be more se rious than forgetting one dose from a twice-daily regimen.

What is “drug resistance”?

Resistance refers to the ability of some types of virus, including HIV, to change or adapt in such a way that the ARVs used to treat them are no longer effective. The main cause of resistance is the failure of patients to take their ARVs in the correct way.

How do I avoid resistance?

Avoiding resistance is one of the most important things to think about when using ARV’s... You need to use a combination that is potent enough to minimise the risk of getting resistance to any of the ARVS you take.

The best chance you have of stopping resistance involves reaching and maintaining undetectable on viral load tests that measure down to 50 copies/ml.

So little HIV is produced at this level that resistance is unlikely to develop to your combination.

As long as you continue taking the ARVs carefully, and as your doctor has told you to, you could use them for many years without experiencing any problems or developing resistance.

What about side effects?

Because the ARVs used to treat HIV are so strong, many people who use them experience some side effects. This is not something that happens only with ARV’s, but is a problem with almost all medication, including traditional and herbal treatment. The type of side effects, how serious they are and how long they last, will differ from one person to the next, and can also depend on whether you are using the medication in the right way.

These are some of the things you should know about side effects:

Most people find that, within a few weeks of starting HIV treatment, side effects reduce and therapy becomes an ordinary and manageable part of daily life.

- Most side effects are usually mild.
- They can often be reduced with other medication that is easy to use.
- There is a small risk of more serious side effects, but these should be picked up by routine monitoring from your doctor.

Ask your doctor, nurse or HIV pharmacist about the side effects related to the ARVs that you use. Ask how likely they are to occur.
Nausea (feeling sick), diarrhoea and tiredness are the most common general side effects. These often become easier after the first few weeks. Very rarely, nausea and tiredness can be very serious. You should tell your doctor about any problems that you may experience.

You can use the table on the next page to guide you through some of the main drugs, the side effects that they cause, and the symptoms that you should look out for.

Table 1: Serious side effects from ARVs

Symptoms in red are urgent to show to your doctor.

Drug name	Side effect	Symptoms
d4T (stavudine)	Peripheral neuropathy (PN)	Loss of feeling (numbness) OR pain in fingers and/or toes
	Lactic acidosis Lipoatrophy	**Feeling sick, vomiting, no appetite, extreme tiredness** Loss of fat in face, arms,legs or buttocks. Veins become more prominent.
3TC (lamivudine)	Hair loss (rare)	Hair thinning or falling out
	PN (rare)	Loss of feeling (numbness) OR pain in fingers and/or toes
AZT (zidovudine)	**Anaemia**	**Feeling tired or weak**
	Lipoatrophy	Loss of fat in face, arms, legs or buttocks. Veins become more prominent.
nevirapine	Liver toxicity	Feeling sick, vomiting, poor appetite, yellow eyes or skin, light coloured stool or dark coloured urine, tenderness or swelling in your liver
	Rash	Redness or small rash on skin
	Severe rash	Any rash over more than 10% of body, any broken skin
efavirenz	Central Nervous System side effects	Mood changes, feeling dizzy or anxious, vivid or disturbing dreams, change in sleep pattern. If severe then urgent to see doctor.
	Liver toxicity	Feeling sick, vomiting, poor appetite, yellow eyes or skin, light coloured stool or dark coloured urine, tenderness or swelling in your liver
	Rash	Redness or small rash on skin
	Severe rash	Any rash over more than 10% of body, any broken skin

Ask your doctor or pharmacist for anti-nausea and diarrhoea medications when you first start therapy so you can use these if you need them. If these medications aren't effective, ask your clinic for stronger or more effective drugs.

Can I change treatments?

If your first combination is too difficult to follow, or if any initial side effects have not improved after the first few weeks or months then there may be an alternative ARV or combination that you can change to.

If this is your first combination, you have more choice. You should not put up with difficult side effects for months on end.

Can I take a break in my treatment?

Once you start treatment, it is best not to take any break or interruption unless your doctor recommends this.

To benefit from HIV treatment you need to take every dose on time for at least six months. Even after this the longer you stay on treatment the longer you can remain healthy.

If you get a very good response to treatment and start to feel better, it is still important to continue taking every dose of treatment on time.

- Stopping treatment for any short period is therefore not recommended. Levels of HIV in your blood - your viral load - can increase again very quickly (from undetectable to several thousand in a few weeks). Each interruption of treatment also carries a risk of developing drug resistance.
- An interruption may be reasonable if you have a very strong CD4 count or have very difficult side effects.
- If you want to take a treatment break, it is essential you talk to your doctor first. Some ARVs have to be stopped all together, and others need to be stopped

Where can people in Namibia access anti-retroviral medication or the treatments for opportunistic infections?

ARV treatment in Namibia is offered at the following government hospitals in Namibia. Call the numbers provided to get more information.

Windhoek Central and Katutura Hospitals	061-2034167
Oshakati	065-2233000
Walvis Bay	064-203441
Keetmanshoop	063-223388
Katima Mulilo	066-253012
Rundu	066-255025

The additional hospitals that will offer anti-retroviral treatment (ART) are the following:

Andara Hospital (Catholic Health Services) (Kavango region)
Engela State Hospital (Ohangwena region)
Gobabis State Hospital (Omaheke region)
Grootfontein State Hospital (Otjozondjupa region)
Nyangana Hospital (Catholic Health Services) (Kavango region)
Omaruru State Hospital (Erongo region)
Onandjokwe Hospital (Lutheran Medical Mission) (Oshikoto region)
Oshikuku Hospital (Catholic Health Services) (Omusati region)
Otjiwarongo State Hospital (Otjozondjupa region)
Outapi State Hospital (Omusati region)

The additional hospitals where PMTCT services will be offered, are: Eenhana State Hospital (Ohangwena region); Khorixas State Hospital (Kunene region); Luderitz State Hospital (Karas region); Opuwo State Hospital (Kunene region); Swakopmund State Hospital (Erongo region); Tsumeb State Hospital (Oshikoto region); Usakos State Hospital (Erongo region).

The government ARV programme will cost you the same amount as a normal clinic visit, but you have a right to treatment even if you are unable to pay the hospital fees.

Non-Governmental institutions like Catholic Health Services also offer treatment in some of their hospitals and clinics. Catholic Health Services provides their services whether you can pay or not, and whatever you religious beliefs are. You should note, however, that you must go the hospital within the district in which you live. This is so that the doctors and medical staff can monitor your progress, as well as do effective follow up care.

To find out more about these programmes, contact the Catholic Hospital in your district, or the one closest to you, at:

Andara	066-259311
Nyangana	066-258266
Oshikuku	065-354550
Rehoboth	062-522006

Anti retroviral treatment is not a cure for HIV/AIDS, but the provision of affordable ARV treatment can effectively break the current connection between HIV/AIDS and inevitable death, and can turn HIV/AIDS into a chronic manageable disease. Access to this treatment can both lengthen and improve the quality of life of people living with HIV/AIDS in Namibia.

It is now widely understood that access to treatment is an essential component of any national response to HIV. The ability to access treatment has had positive effects on the numbers of people who are willing to have themselves tested, as well as lowering stigma and discrimination in communities where there are treatment programmes.

Accessing treatment will create an opportunity for people living with HIV/AIDS in Namibia to continue contributing to Namibian society, to care for their children and loved ones, and, most importantly, to carry on living.

Adherence diary

Schedule planner:

Use this top chart to plan your regimen timetable with your doctor, nurse or pharmacist. Use shading to indicate when you must not eat if you are using ddI or indinavir and meal times for drugs that you have to take with food such as nelfinavir, ritonavir and saquinavir.

	AM							PM												AM		
Drug name	6	7	8	9	10	11	12	1	2	3	4	5	6	8	7	9	10	11	12	1	3	2

Adherence check:

Once you have worked out a daily regimen above use the table below to mark off each dose after taking it for the first few weeks. Write the name of the drug and the time you need to take it in the top boxes. Use a different box for each drug. Then tick off the dose and write the time you actually took the dose in the sections underneath. Use a photocopy, or draw a new version yourself to use for the second and third weeks or if you need a larger table. This will help you know how well you are doing and this will be helpful when you next see your doctor.

Week date: _____

add drug names + times from the schedule above in these boxes	Drug names + times:AM			Drug names + times:PM		
Monday						
Tuesday						
Wednesday						
Thursday						
Friday						
Saturday						
Sunday						

write the actual time that you took each dose each day when you tick off these boxes

Treatment for HIV and your Rights:

Your rights as a patient...

To be fully involved in all decisions about your treatment and care.
To be treated with respect and confidentiality.
For your records to be kept securely. They should be available for you to see if you ask.
To make a complaint about your treatment. Any complaint must be fully investigated.

If these rights have been violated, or if you suffer any discrimination because of your HIV status, do not remain silent!

Contact the AIDS Law Unit at the Legal Assistance Centre. Our contact details are:

Telephone: 061-223356
Fax 061-234953

e-mail us at: aidslaw@lac.org.na

There are a number of good resources on treatment available on the internet:
www.i-base.org.uk
www.tac.org.za

ded
Deutscher Entwicklungsdienst

fhi Family Health International