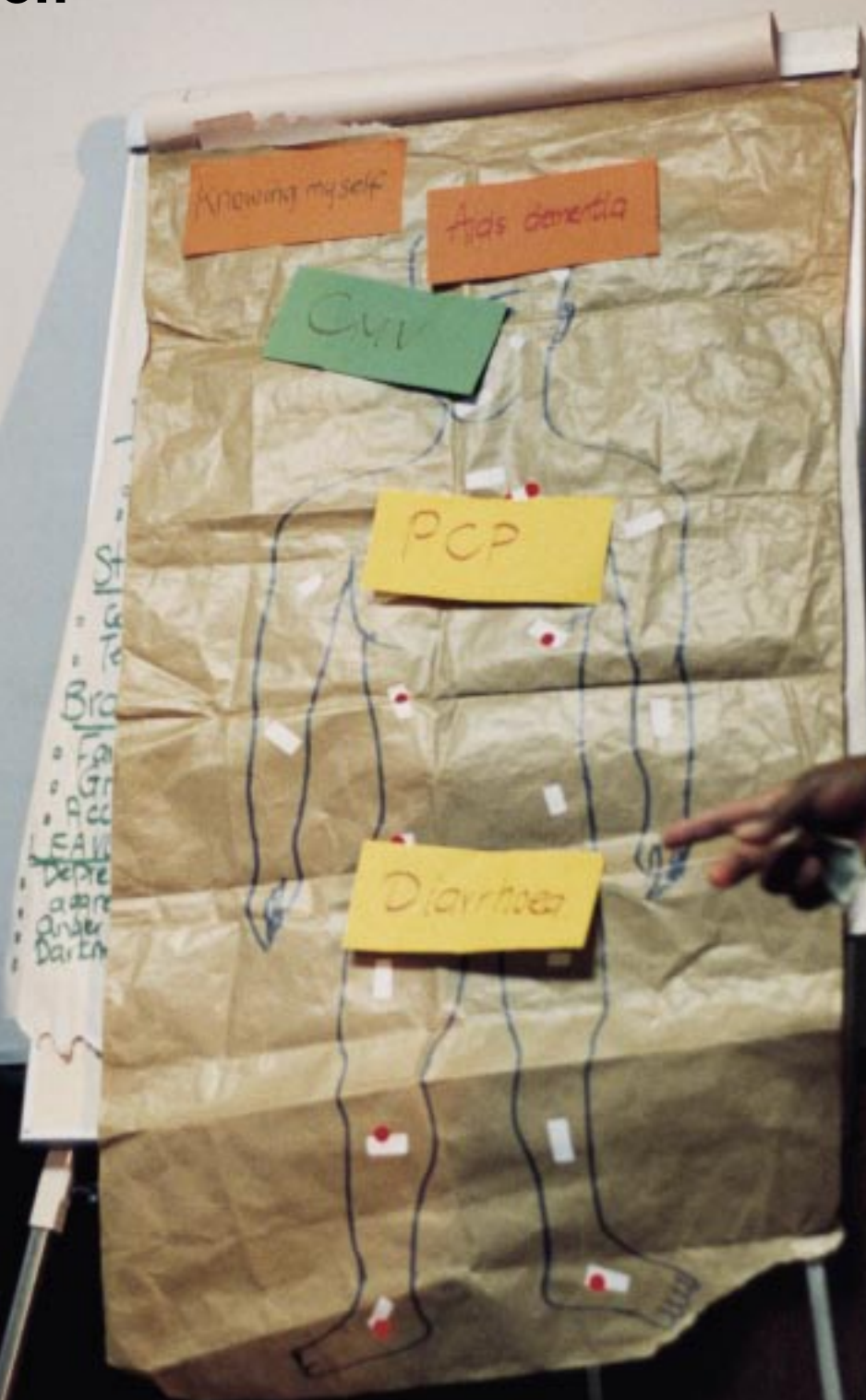


Why we must provide HIV treatment information



Most people who test HIV-positive go through similar experiences.

The shock of diagnosis, isolation, denial, sometimes prejudice.

But almost right away there is the need for information:

How long will I live?

Can I get treatment?

Does the treatment work?

Are there side effects?



Simon Collins UK

Learning to save your own life

Treatment literacy begins when a person asks the first question: What is the virus? What is the CD4 count? It continues as you ask for more information.

If you keep asking questions, eventually you get an answer you understand. Soon you can answer for yourself, your friends and your communities.

These are the politics of treatment literacy. You have a basic right to understand your body and health; choose and have access to free treatment; have information about treatment choices.

HIV has brought a radical change in how treatment and information about treatment is delivered. You begin by trusting in your doctor – but doctors have limited time and resources. Doctors speak a different language.

Who has the best interest in you having the best health? Who has the best potential to make treatment work for you?

You are the one who has the greatest interest in your staying alive.

What is the role of HIV-positive people in treatment literacy and peer advocacy? The experience of being a patient is often just as important as medical training. Patients are highly motivated. They want to live.

You get better health outcomes from greater involvement of people in their health care. In a Uganda clinic I visited, people who started treatment, who became stronger and got their health back, worked as treatment counsellors for the next group of people starting treatment. They have 99% adherence in that clinic.



Vuyiseka Dubula South Africa

Many nurses not trained in HIV. They are seeing patients with opportunistic infections but they are not allowed to prescribe certain medications – fluconazole, for example – because only doctors can prescribe it. But the doctor only comes once a month. The nurses see people who are sick but can't help them. They tell them, "Go home, there are no fluconazole tablets."

If a nurse tells you there is no medication and turns you away, then the next time you won't spend your money for transportation. So, you take a five minute walk, and see a friendly face at the traditional healer. They will take time with the patient and that patient may not go back to the HIV clinic. That's why some people will opt for spiritual healing and look for purification with bleach or something like that.

Our treatment literacy practitioners are in the clinic to educate people about what to expect before they start treatment. There is limited time to explain everything when a patient sees the nurse, but if the treatment literacy practitioner has explained things the nurse can spend only five minutes instead of an hour. Treatment literacy practitioners can also do voluntary counselling and testing (VCT) and relieve the burden on nurses. There is only one pharmacist for 500 people, so our practitioners can also be trained as assistant pharmacists. Treatment literacy practitioners are now participating on some clinic committees.

90% of people using public healthcare system are poor people. Only 10% of our population uses the private sector – but more money is allocated for the private sector than the public.

In the private sector you will not come into contact with a treatment literacy practitioner and you may never hear about side effects and learn the things you need to know. So going to the private sector also has disadvantages.

A big problem for us in South Africa is our president and our Minister of Health. Our president says there is no health care crisis in our country. But isn't having only one nurse for 500 people a crisis?

Irina Deobald Russia

Why treatment literacy?

In one Russian region there was a shortage of drugs and people started taking half of the dose. But this meant they could develop resistance. The drugs were back in stock again in a few weeks, but they didn't know how to correctly manage the interruption. They didn't have the correct information.



Paul Kasonakoma Zambia

We heard of a person who went to a conference and ran out of his medicine. He then came home and counted the number of days he missed, then took them all at once. He died. He didn't know better.

People are afraid of the drugs. If you ask the average Zambian about antiretrovirals (ARVs), they say the person with HIV on treatment dies like a pig – fat, instead of skinny like with AIDS. We say, "Look, we are taking these drugs and we are living." This makes a lot of sense to people.

We see many side effects with stavudine – peripheral neuropathy and lipodystrophy. People don't have the capacity to go back to the doctor and say, "This is not working for me." If people on treatment know how to recognise these symptoms in the early stages, then they can change drugs before it is too late.



Johanna Ncala South Africa

In South Africa we are still fighting the bad information spread by President Mbeki and Mattias Rath. (Rath sells vitamins as a cure for HIV and tells people that ARVs are poison. Mbeki doubts that HIV causes AIDS.)



**Francina
Lusungu Nyirenda
Malawi**

You can put people on ARVs, but without information there are problems. We want people to know about the effect of stopping the medications. We want them to know that they must continue for life.

In Malawi, we don't have information in our own local languages that people can understand. We have most of the literature in English, and it is a matter of translating it so more people can understand it.



Loon Gangte India

Rajiv Kafle Nepal

I know four families who sold everything they owned to get ARV drugs for a family member with HIV. They didn't know that treatment was for life, and when they used up their money, the HIV viral load bounced back and two of them died.

I went to a TB conference last year and they talked about the rewards they give patients for taking their drugs, and the high tech bottles that beep and have LCDs in the top that tell when you opened it. Isn't it better for people to understand why they are taking their drugs instead of giving them rewards for taking the drugs?

We have come out with ten booklets and several fact sheets. We were influenced by the early TAC posters. In our next set of posters we will have people representing the messages in the posters. We use a lot of materials from TAC. We used other sources like i-Base to make our training manual and treatment literacy books. We wanted to share our materials with our Indian friends as well and we translated the materials into Hindi so they will get inspired to make treatment materials.

After producing five books, our volunteers have learned so much. It is really empowering for them. We talk about every detail down to the kind of paper we use.

We had to work with the language. A lot of the i-Base concepts were specific to the UK and we had to change those. Many of the brand name drugs mentioned are not available to us, so we use the generic names. There are possible double meanings and difficult grammatical points. Someone translated the meaning of "prevention during labour" in the booklet as "preventing HIV while at work."



Antiretroviral Therapy (ART)



ART will help you feel strong even if
your immune system is weak





Sibonelo Mduli Swaziland

Julius Amoako Ghana

César Mufanequiço Mozambique

In Swaziland, we have the paternalistic approach to HIV treatment. People are just given the pills and told to take them at 8.00 in the morning and at 8.00 at night. There is no explanation at all.

The drugs are there – we don't have a problem with the drug supply. But all our posters and education are talking about prevention – which is OK – but we need information about treatment too. Lately we are moving backwards. The government thinks that if too many people learn about treatment then too many people will demand it and it will create a problem.

There are many taboos in my country and illiteracy is high. If you speak about HIV in Mozambique, they think it is a death sentence. In the rural areas if someone has herpes zoster, they say they were bewitched. We need to educate people. We have community training programmes. We teach people how to identify and treat opportunistic infections and what to do if they see the symptoms in their bodies.

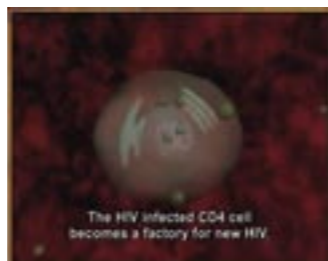
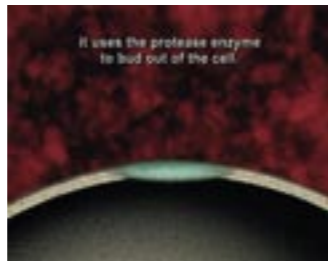
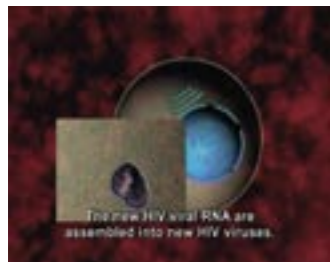
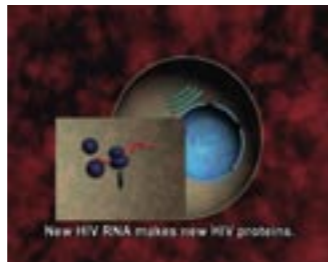
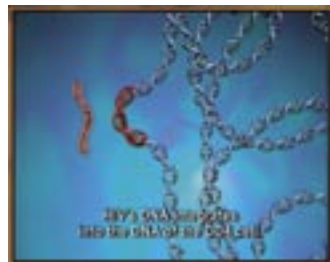
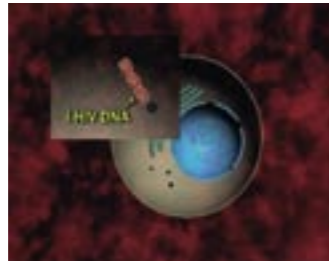
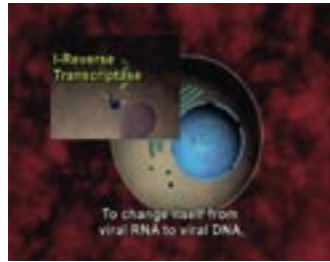
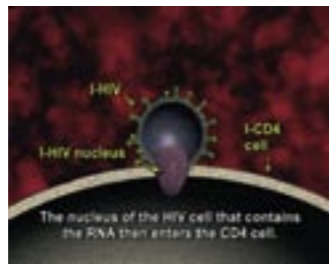
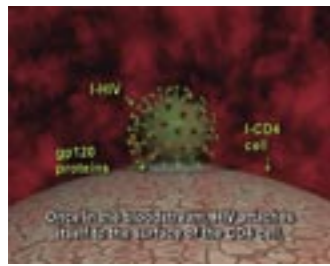
But people ask, "Where did you get this information?" They say, "You can't tell medical professionals about your symptoms or what kind of medicine you should take." But we say, "You are helping the doctor because you are the person who has to take the medicines."



Sipho Mthathi South Africa

Traditional medicines have been used for a long time and people see that they work to take away symptoms, but they are being used politically to divert attention from ARVs. In TAC we have struggled internally about the role of traditional medicine. Research on traditional medicines has not been funded. Traditional medicines have not been researched and validated the way ARVs have. But they are being used by politicians to undermine choice.





We need to understand that! ->
- There are some issues that makes a person to suffer... becz of many things

How is Life

ROOTS [Sufferings] = through abuse

- rape • violence • sexual Abuse
- early pregnancy - Lack of knowledge
- Curiosity etc

Stem [lead to shame/victimness as a results of affected

- Community - Parents - families - friends
- Teenagers / Youth / Children as well

Branches: [support systems

- Family supports (friends)
- Grants (socially issues)
- Access Rx / ARV's
- LEAVES (Results)
- Depressions / self blames - filthy feelings
- aggressive / isolation
- Order to outside life
- Darkness - Lose Hope



**Siama
Abraham Musine
Kenya**



If people think the cause of AIDS is bad will between men and women, we ask them, "Then how do you explain that babies also have HIV?"



Sibonelo Mduli Swaziland

Roman Dudnik Russia

Many people fear taking ARVs, because they think it will make them worse. They don't know about the side effects, but because they know people who have died after taking ARVs, they think it was the drugs that killed them. Some people die just because they were not treated in time or they were treated too late. We've also been taught you cannot take the traditional medicines along with ARVs. So people stop their ARVs.

We have rapidly increased access to treatment in Russia. But we don't have enough patients because they don't know they are infected...or they are afraid of side effects, or they are afraid to come back to clinic because they have a bad relationship with the doctor.

It was good that the government bought a lot of drugs, but they didn't think about the information. Our role is to provide this information.

We are developing materials to inform people that treatment is available and motivate them to get tested.

There have been rumours that the drugs are rejects from the US or are cheap brands. We are a traditional country and have traditional medicine, so we have people stopping ARVs to take African potato or other traditional medicines. We also have paternalistic doctors, who say you have to take these pills at a certain time, and if you ask too many questions you might get in trouble. And people in rural areas – especially women – don't have money to travel to the clinic even if the treatment is available.



Paul Kasonkomona Zambia

Treatment literacy for whom?

We have deaf people coming to us now for treatment information and we are finding new challenges there. They translated the “positive” in HIV-positive as “something good” in sign language.

We need to target messages to disabled people. We need simple materials that can be used with people who are deaf or blind.

Children often don't know what they are taking. The mothers remove the labels from the bottles. But one child saw the label and figured out that she had HIV, because she had seen treatment information.





Julius Amoako Ghana

The posters I take back from TAC really speak about treatment education. Everybody at my hospital sees the posters. Everybody at my church sees the posters. Then they realise that, if there are really these drugs, then my brother or my girlfriend did not have to die from AIDS.

Johanna Ncala South Africa

How to do treatment literacy

In 2003 TAC started treatment literacy programmes. We call our treatment education workers “treatment literacy practitioners,” which helps with their being accepted by medical professionals. Once the medical people see we help get people on treatment, they want more and more treatment educators from TAC to come into the hospitals.







Sostain Moyo Zimbabwe

Chris Green Indonesia

The field of medicine is highly protected in my country. For example, we have nurses who are trained to do rapid HIV testing, but the lab workers don't allow anyone else to perform the rapid tests, so not enough tests are done.

If we take up the TAC model of adherence practitioners in the hospitals, they will protest that only medical people can offer treatment information and counselling. How did others overcome that protected discipline?

One of our jobs is to translate between the doctors and the people in our constituency. We have to understand both the language of the people and the medical professionals.

If we go to the doctors and say one of our friends got better because of this or that, they will not accept it. It is anecdotal information. You have to bring them the medical literature and say: "Here is why we believe this."

Simon Collins UK

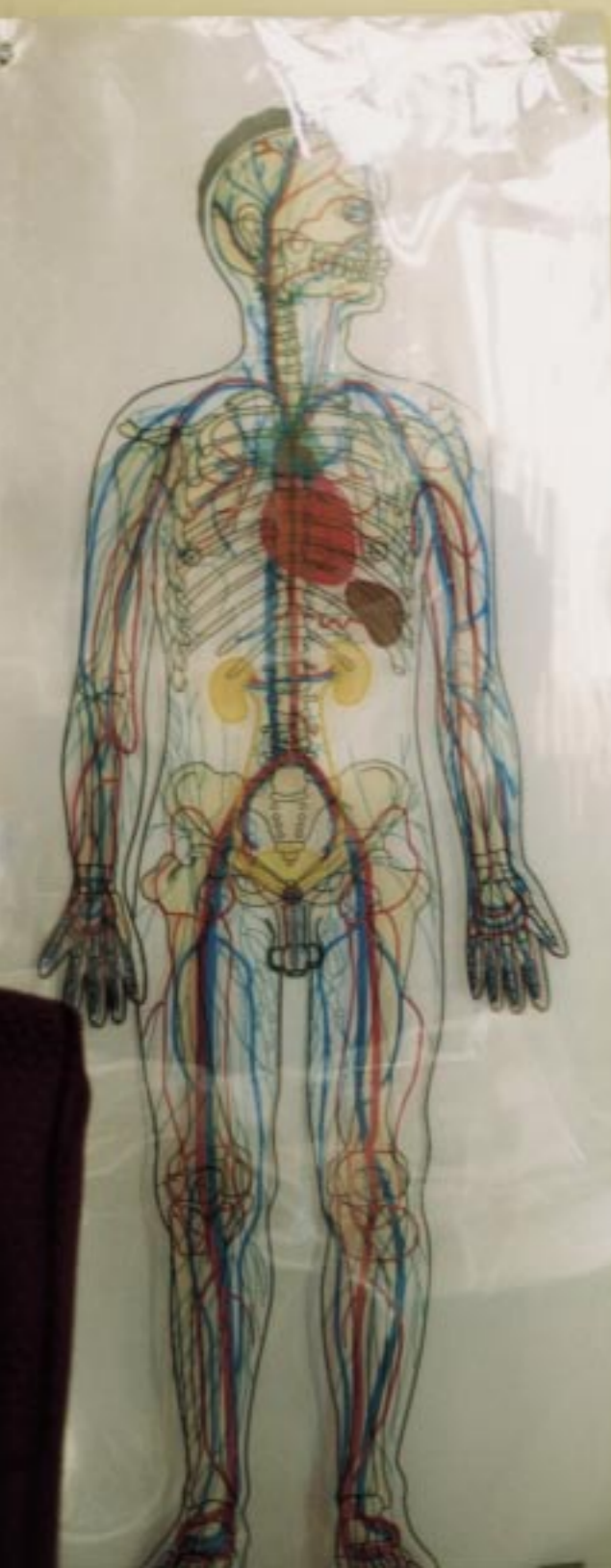
Siama Abraham Musine Kenya

If your Prime Minister becomes ill, he will ask a doctor about his health. So it is natural that he thinks the same is good for you too.

We have learned the language that doctors use. We go to the scientific literature to find out what is true. Because you are in a difficult situation, you are trying something radical, and they are threatened by this.

I need to know how to go about giving information to the church leaders. The church leaders say if you are faithful to God, you will be healed. Most of our people who die are dying through the churches.






Positive Living Handbook

What are antiretroviral (ARV) drugs?

Antiretroviral (ARV) drugs help reduce the level of HIV in your body. They do not cure HIV, but they can help you stay well for longer.



ARV drugs slow down the speed at which HIV attacks your immune system. The drugs slow down the HIV copying itself, and increase your CD4 solidier cells, so that your body can fight off opportunistic infections.


Remember: When people take ARV drugs, they don't fall sick as often and feel better for longer periods of time. Once you start taking ARVs, you must take them each day, at the right times, for the rest of your life.

i

How do ARV drugs work?

HIV attacks your CD4 solidier cells, weakening your immune system. Over time the number of CD4 cells drops.

Once you start taking the ARV drugs, your immune system should become stronger and your body will be able to fight infections better. The number of CD4 cells in your body can also increase.



The HIV will not fully disappear, but will be sleeping in your body. This is why you can still infect someone else even though you feel much better.

ARV drugs usually come in the form of tablets or capsules. Children can take a syrup form of the drugs, which are easier to swallow.

92 Treating HIV - ARV drugs 93 Treating HIV - ARV drugs

Loon Gangte India

Simon Collins UK

Our job is hard. We have to learn from the scientific knowledge and put it into the language of our people. Still, the scientists can't study everything. Deciding what is best to do for an individual still depends on understanding that person.

None of this is fixed. The information we give out today is based on the best we know now – but in a year it may be different. If it is, then community treatment advocates are likely to be talking about this earlier than many doctors.



Rajiv Kafle Nepal

We had no formal written proposal or mechanism for adapting these materials. In the past we worked with Family Health International and had to go through many cycles of review, but not when we adapted the i-Base materials. We included things in our books that are not in the national HIV treatment protocol. But our goal was to include the information we thought was important – that we thought should be shared. For example, we had a chapter on sperm washing, and a government officer was upset with this. But we didn't care. It was important for people to know that this was available in some countries.

After the books were developed we ran training workshops and we got feedback from the people who used the materials. After two years of working on this, I see changes in the community. I hear people talking about how a specific drug in their TB regimen is interacting with other drugs in their HIV regimen. A few years ago no one was on ARVs and now they are thinking about interactions with their ARVs.

There are two major types of RTIs: Nucleoside RTIs (NRTIs – nukes) and Non-Nucleoside RTIs (NNRTIs – non-nukes).

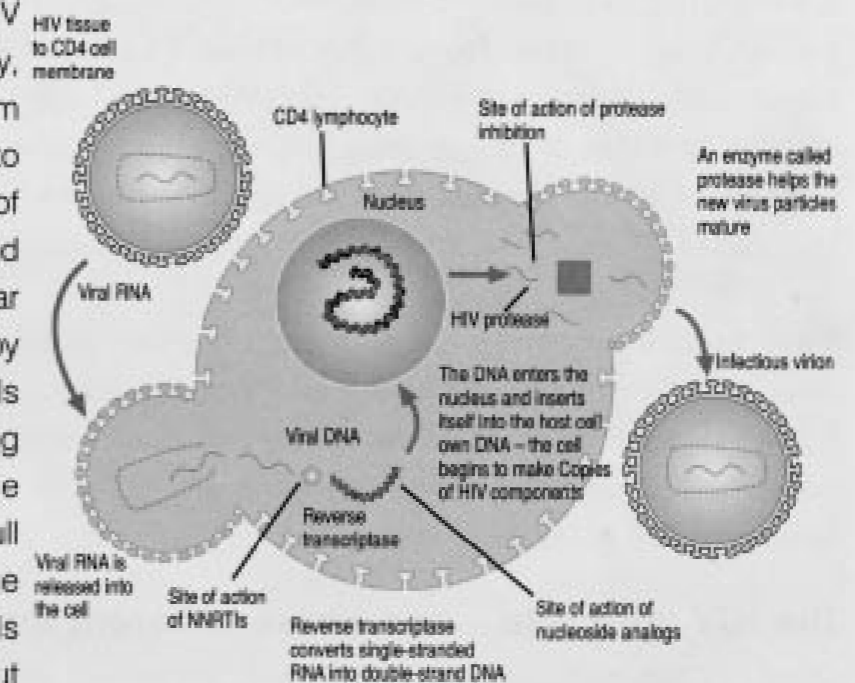
How does the NRTI family work?

Nucleosides are building blocks which float in the water-like fluid inside the cell (cytoplasm). These building blocks are required to make the RNA into DNA.

The NRTI (nuke) class of drugs look like real nucleosides but really they sabotage the transcription process for HIV because they are the wrong shape. The DNA chain can not be made because the NRTI nucleosides cannot be connected to the real nucleosides.

How does the NNRTI family work?

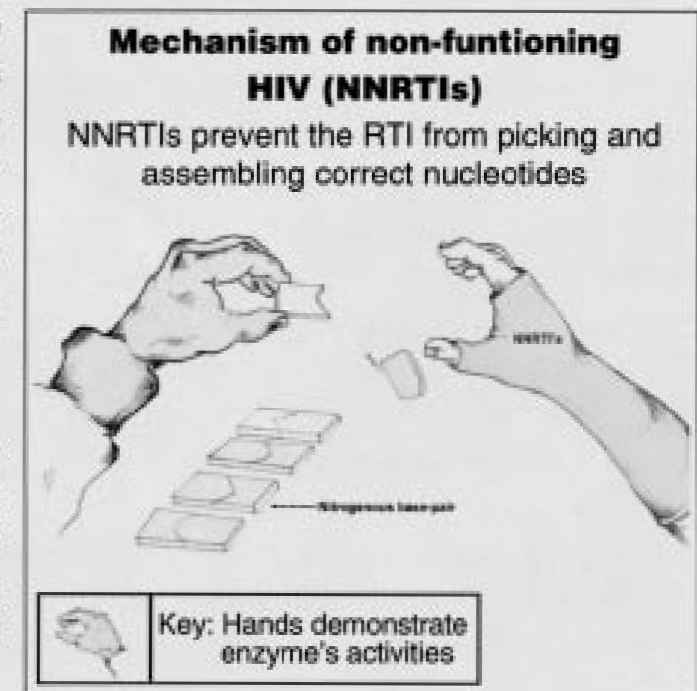
The NNRTIs (non-nukes) inhibit HIV replication in a slightly different way, but they also prevent the HIV RNA from becoming DNA. Imagine if you needed to pick something up but you had a block of wood glued to your hand. You couldn't bend your fingers to grab anything. This is similar to what the non-nukes do. NNRTIs work by directly binding the RT enzyme. The NNRTIs block the RT enzyme from connecting nucleosides together by attaching to the active site of the enzyme. This stops the full chain needed to make a DNA copy of the HIV RNA from being completed. NNRTIs block the work of the RT directly, without mimicking building blocks.



How does the Protease Inhibitor family work?

If HIV RNA has been made into DNA, then a Protease Inhibitor (PI) is used to prevent any more HIV virions from being made which can infect other cells. The HIV DNA is made into RNA which must be cut by protease and then assembled in order to activate the new HIV virion. Without being activated, the HIV virion will not be able to infect a new cell and will be destroyed by the body.

The enzyme that works like scissors to cut up the HIV RNA is called protease. PIs work by interfering with the scissors so they cannot cut. Even though the HIV has reproduced inside the cell, by blocking protease HIV cannot be processed to leave and infect another cell.



Linda Mafu South Africa

Issues about sex are difficult. We need to find the right words that people use in the local community; words that are comfortable for them.

We use songs to teach about side effects and treatments.

It is important to be a part of the community so we do not insult the people we are working with.



Simon Collins UK

Someone had to invent these terms in the first place. The community quickly replaced the term “treatment compliance” with “treatment adherence.” We use “HIV-positive” instead of “HIV-infected.”



Choices for your next combination

Which combination to change to

The combination you choose will depend on your previous drug history and your current test results.

It will depend on the reason that previous combinations failed and the results of the tests listed on pages 10 and 11.

Second-line therapy

(If your last combination was the first time you used treatment.)

All PIs have some cross-resistance to all other PIs, and all NNRTIs have cross-resistance to other NNRTIs. It is therefore probably safer to switch this part of your combination, even if a resistance test did not show resistance to these drugs.

- If you previously used an NNRTI-based triple combination, then you can now use three or four new drugs including one or two PIs.
- If you previously used a protease-based combination, then you can use three new drugs which now include an NNRTI.

The recommendation for someone whose first combination has failed is to switch to at least three completely new drugs.

Protease after protease

If you change a single protease-based combination early enough, you can change to a new protease inhibitor, boosted by ritonavir, in a four-drug combination. You could also change to newer PIs that may be less cross-resistant.

- The earlier you change from the first combination, the more likely that your next combination will be successful.
- Using ritonavir-boosted protease inhibitors result in a more potent therapy.
- The chance of success is related to being able to change other drugs at the same time.

Using two new nukes (d4T, AZT, 3TC, FTC, ddI, abacavir, tenofovir – though not d4T and AZT together; or tenofovir and ddI together) will give the strongest response.

Cross-resistance between nukes is very complicated, and is the subject of ongoing research. If you have developed resistance to AZT and 3TC then abacavir or tenofovir may or may not work well – depending on the exact pattern of mutations. If you have developed resistance to abacavir then 3TC or FTC will not work. The significance of cross-resistance between AZT and d4T is not clearly understood.

How to choose new drugs

Trial results, even for new drugs, are not always very helpful in predicting how well a new drug will work in people with different patterns of resistance.

However, there are some general principles that will increase the chance of your next treatment working:

- If you can use a drug from a new class
- If you can use drugs from classes you have used before, but not developed resistance to (ie switch while your viral load is still low)
- If you use more, rather than fewer drugs, you may get added benefit from all of them together.

Using up options

'Using up options' is often given as a reason for holding back some drugs. However, this means that the regimen used is not as potent as it could be. Although you may be using your last unused drug, it may provide the extra power you need. There are few reasons to save just one drug on its own if you really need a treatment now.

An exception to this would be if you know another new drug will definitely be available in the near future. In this situation, it may be better to wait for the new drug before changing treatment.

This is especially the case if your viral load is stable (at any level). Starting all new drugs together will be stronger than starting them in a staggered way.

Expanded access programmes let you use new drugs before they are licensed. This is after research has shown they are effective but before they are fully approved. Most new drugs are provided in this way but it is sometimes very difficult to know when each programme will start.



Vuyani Jacobs South Africa

Our TV programme *Beat It* is watched by nearly a million people each week. *Beat It* is a bridge between HIV activists and government officials. *Beat It* has made a big difference in people's lives. All the materials are positive, never negative. People say, "I know you from *Beat It*" and they tell me they are on ARVs.





Lulekwa Dlelaphantsi Nombasa Gxuluwe South Africa



We provide education in clinics, in churches, and schools. We do the virology; looking at the scientific study of the virus itself. We look at the life cycle of the virus. We look at the body and study the cells, the tissues, the organs, that make up the person. Then we look at the OIs (opportunistic infections). We look at what is happening to the body when a person has shingles. Then we look at the treatments that are available in the public health settings.

We use songs to mobilise people, so they know what is happening. Songs can deal with the politics within the HIV sphere. Educational songs deal with shingles, TB – different types of TB. If it is in the head, we point to the head while we are singing.

Here are three songs that we sing in English:

“You better change your mind.
You better condomise.”

“You do PMTCT where you are.
You do PCR where you are.”

“All over, the world is talking
about antiretrovirals.”

In dealing with the HIV lifecycle, we do the scientific explanation, then we have the participants act out what is happening in the human body.

We try to simplify the scientific terms so as to reach the masses of people, who are mostly illiterate.

We refer to the immune system as the soldiers of the body. What is the role that the soldiers play in the body in protecting you from the invaders? Here comes HIV. Now the soldiers of the body can't function properly anymore. Other people use the example of a football team to show how the virus operates in the body.

We talk about the proteins as the building blocks or bricks used to build other parts of the body. Instead of saying the gp120, we say “the key that opens the lock” so that the virus can come inside the house.

People act out the parts of human cell and the virus. When the gp120 meets the human cell, the cell opens and the three enzymes and the RNA enter the human cell.

RT (reverse transcriptase) attaches to the nucleotides and changes the RNA into viral DNA. It must be double stranded. Then integrase enters the nucleus. It puts the viral DNA into the human DNA. Then the nucleus does its work, which starts to manufacture more proteins and more viruses. They come out as a chain of proteins. Then the protease is waiting to cut the chains so the new virus can go off with part of the cell membrane.

Artur Ovsepayan Ukraine

In our country, we are not as open and it is difficult to ask people to sing or dance. In our education, we use methods like asking people how they understand HIV and how they learned about HIV.

We always have three main topics that people want to talk about:

“Is HIV a punishment from God?”
“Did it come from space?”
“Is it a result of a pharmacological experiment?”

Doctors are not able to explain what they know in ordinary language. So we have doctors participate with HIV-positive people in our seminars. This helps to bring both groups to the same level and get them to come to the same conclusions about how to solve the problem of HIV. So we try to decrease the boundaries between doctors and patients. We use this game as a starting point and then move to more complicated topics.

After we demonstrate the HIV lifecycle we divide into three smaller groups and ask people to demonstrate the different lifecycle stages. After that exercise it is easier to explain the classifications of antiretrovirals and how they work. It is very important that everyone can explain how the ARVs work and can pronounce their names. When participants can repeat what you have told them, then the information will stay in their minds longer.



Sipho Mthathi South Africa

I may have a different theory of ill health than the germ theory. In the rural areas, there is often a very different understanding of ill health. What do you say when people say, "I don't have a virus, I have been bewitched"?

How do you integrate other belief systems to promote the understanding you want to promote? If I don't understand germ theory, how can I even understand what you are saying? How do you start from where people are?



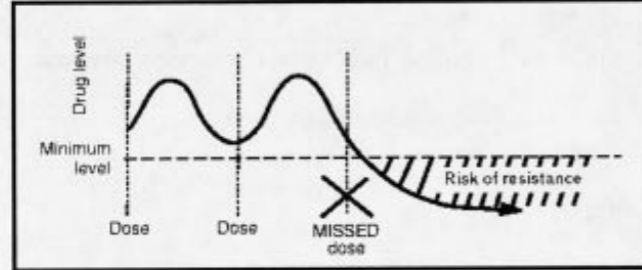
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- शरीरबाट छिटो सफा हुने औषधीहरू छोटो छोटो समयको अन्तरालमा खानु पर्छ र ती औषधीहरू जसलाई सफा गर्न बढी समय लाग्दछ । यी औषधीहरूको दुई मात्रा बिचको समय लामो गर्न सकिन्छ ।
- केही औषधीहरू जस्तै एचआईभीका औषधीहरू, क्षयरोगका औषधीहरू, एन्टिवायोटिक र एन्टिफंगल औषधीहरू एउटा निश्चित मात्रा भन्दा सधै बढी हुनु पर्दछ जसले गर्दा प्रतिरोध उत्पन्न हुन पाउदैन ।

एउटै मात्राको औषधी खाने फरक-फरक व्यक्तिहरूमा यसको धेरै फरकिलो विविधता (भिन्नता) हुन्छ भने सभन्नु महत्वपूर्ण हुन्छ । केही व्यक्तिहरू औषधीलाई छिटै टुक्र्याउन काम गर्छन् र यसले औषधीको मात्रा एभरेज भन्दा बढी बनाउँछ । अर्को शब्दमा भन्ने हो भने, प्रत्येक मात्रा औषधी पश्चात् एउटै समयमा एउटै व्यक्तिमा औषधीको मात्रा नापियो भने औषधीको मात्रामा फरक हुन सक्छ । केही औषधीहरूको मात्रा विहानी मात्राको १२ घण्टा पछिको र रात्री मात्राको १२ घण्टा पछिको औषधीको मात्रामा फरक फरक हुन्छ ।

फेरी व्याख्या गर्न ग्राहो हुन सक्छ । त्यसैले साधारण चित्र नै बुझ्नको लागि महत्वपूर्ण हुन्छ : हाम्रो लक्ष्यहरू भनेको उपचार हुदा औषधीको मात्रा ठीक र सुरक्षित हुनु हो ।

औषधीको मात्राको ग्राफले हामीलाई नियमितताको बारेमा जानकारी दिन्छ साथै औषधीको एक मात्रा दिलो खाएमा वा पुरै मात्रा खान बिर्सदा के हुन्छ भन्ने जानकारी दिन्छ ।

तपाईंलाई याद छ भने लगभग चित्रले माथिल्लो र तल्लो वास्तविक मात्राको रेन्ज जनाउँछ, जुन व्यक्तिहरूले कम मात्रामा औषधी सेवन गर्दछन् उनीहरूमा यदि औषधीको मात्रा खान दिलो भयो भने वा पुरै मात्रा खान बिर्सियो भने उनीहरूमा औषधी प्रति प्रतिरोध उत्पन्न हुन सक्ने संभावना बढि हुन्छ । कहिलेकाही बिर्सनु वा खान दिलो हुनु (मानौ महिनामा १ पल्ट) ले त्यही फरक नपार्न सक्छ । तर यदि बिर्सनु वा खान



प्रत्येक समयमा जब हामी औषधी खान्छौ, औषधीको मात्रा आवश्यक तल्लो तह भन्दा माथि रहन्छ ।

मात्रा खान बिर्सिदा यदि हामीले औषधीको मात्रा खान दिलो गन्यौ वा पुरै मात्रा बिर्स्यौ भने हाम्रो रगतमा औषधीको मात्रा हाम्रो रगतमा सुरक्षित तल्लो तह भन्दा तल भर्दछ । औषधी प्रति प्रतिरोध उत्पन्न हुन्छ ।

दिलो हुनु प्रत्येक हप्ता हुँदैछ भने यसले भाईरसलाई प्रतिरोध उत्पन्न हुने सम्भावना दिन्छ ।

नियमितता भनेको डाक्टरले भनेको भनेर सबै चिज समयमा गर्नुमात्र होईन । यो भनेको हाम्रो शरीरमा औषधीको मात्रा सुरक्षित तल्लो तह भन्दा माथि नै राख्नु हो । उपचारमा रहदाको पुरै १०० प्रतिशत समय यसरी रहनु पर्छ ।





Roman Dudnik Russia

We adapt existing treatment materials. We adapted a Dutch training model to our setting. It begins with an initial three-day face-to-face meeting, then continues with a four-month internet-based distance learning phase. The exercises progress in difficulty from week to week. You can work individually or as a group. At the end you send your work to the moderator for evaluation and take a test.

Loon Gangte India

There is nothing in Hindi for the real people who need it. We are having the first treatment workshop in Delhi. We take treatment information materials from all over on the internet. We will take all this and feed all the wisdom into our treatment handbook. I'm crazy about simplified, non-technical and localised language. I don't yet know how to document all this wisdom into a form I can use. We are observing.

The language people are using has changed. They are talking about adherence and side effects now. In our country you need to translate materials into at least seven languages. I might be missing something, because all I know is I want something in Hindi.

Paul Kasonkomona Zambia

We did the role play with the gp120 and the CD4, because people always wonder why the HIV follows the CD4 cell.



Siama Abraham Musine Kenya

At the first treatment literacy training we show people how to communicate with medical people and how to ask for what they need. Now we have people getting to the clinic before they have AIDS, which is much better.

If you are treatment literate, then you know how to recognise the infections and prevent them. People now go to the clinic about their symptoms and get proper treatment. They demand the treatment.

The T-shirt really breaks the silence. The people see it and want to know more. It used to be I put it on and all the people run away. Now they want to stop and talk to me and learn more about HIV.



Think of your body like a house. If you look after a house nicely, it will last longer. If you don't look after the house, the rain will be able to get in. Opportunistic infections enter the body the way rain enters a house that is falling apart. Just as a house that is kept well lasts longer, a person who takes good care of him or herself will live longer.





Irina Deobald Russia

ARVs are now available through the government, but there is still a lack of information. People are afraid of side effects, but the medical people don't have time to discuss the side effects.

The medical staff does not have the time to communicate with the clients. We have peer counsellors to give information and their own experience. We have different printed materials. We do trainings and workshops for people with HIV. I hope to find new tools to make the information we have more accessible. We need to use common language more. We need cooperation with medical workers and state structures.

Gregg Gonsalves USA

**Treatment
literacy
when?**

Now!

It is one thing to learn the doctors' language, but there is still great resistance to community-based literacy by governments. This is a political struggle. It will be hard. We know that treatment literacy works – there is scientific evidence to say it works. But it will take campaigning and lobbying and struggle to make it a reality.





Johanna Ncala South Africa

I came to TAC thinking I knew about treatment because I was a nurse and came from a medical background. But TAC taught me to not just to take things on faith without asking why. Now we are asking, "Why I am doing this? Why this is happening in my life?" I've learned to be assertive and stand up for what I believe - to not be ashamed or hide that I am taking my ARVs.



Paul Kasonkomona
Zambia

Sipho Mthathi
South Africa

We have even pushed the government to put people in prisons on ARVs.

Science is very much about power and no one willingly gives up power. How can we reclaim science and make it about helping our communities?



Rajiv Kafle Nepal

Doing treatment literacy work is different from other work as an AIDS activist. It is more like being a teacher. I really enjoy the work I am doing these days.





From the June 2006 HIV i-Base guide Introduction to Combination Therapy

What, when, why and other questions.

This guide is mainly written for people starting their HIV combination, and for anyone currently using HIV treatment who was never given support information before they started treatment.

What is antiretroviral combination therapy?

Combination therapy is the term for using three or more drugs to treat HIV. It is also called triple or quadruple therapy or HAART (Highly Active Antiretroviral Therapy). HIV drugs are also called ARVs. These drugs work in different ways and at different stages of the HIV life cycle.

Do the drugs really work?

In every country that uses ARVs, there has been a dramatic drop in AIDS-related deaths and illnesses.

Treatment works for women, men and children. It works no matter how you were infected with HIV. Whether this was sexually, through IV drug use, or by blood or blood products. Taking HIV drugs, 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.

Regular monitoring, using blood tests, will check that the drugs continue to work.

- Viral load tests measure the amount of HIV in your blood. Results are given as copies/mL.
- CD4 tests measure how strong your immune system is. Results are given as cells/mm³.

Even if you start with a very low CD4 count, 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 well much longer.

How long will the drugs work?

Combination therapy using at least three drugs has now been used for over ten years. Many of the individual drugs have been studied for even longer.

The length of time that any combination 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 many years.

UK guidelines state that getting your viral load below 50 is a main goal when starting treatment.

Does everyone need treatment?

At some point, most HIV-positive people will need treatment, though when people will need it can vary a lot. HIV infection progresses in different people at very different rates.

- About one third of HIV-positive people will stay well for up to 10 years after infection, even without treatment.

- About 60% will start treatment after 4-5 years.

- 2-3% of people can become ill more quickly and need treatment much earlier.

- 2-3% can go for 15-20 years without treatment.

Whether you need treatment is something you have to discuss with your doctor. This will usually take place over several visits.

When discussing treatment

- Ask as many questions as possible until you are happy with the answers.

- Get useful information from other sources. This includes the internet, friends, newsletters and phonelines.

Even if you are well, it is a good idea to get to know something about treatment now, before you need it.

This is particularly important if your CD4 count is falling, or if you have a high viral load.

When should I start treatment?

When to start treatment is something you and your doctor must discuss together. You are the person who has to take the pills. So, you have the choice over whether you start, as well as which drugs you use.

It is recommended to start treatment before your CD4 count falls below 200. Even at this level, there is unlikely to be an urgent need for you to start treatment straight away, if you are not ready.

- Ask your doctor to tell you about the different drugs 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.

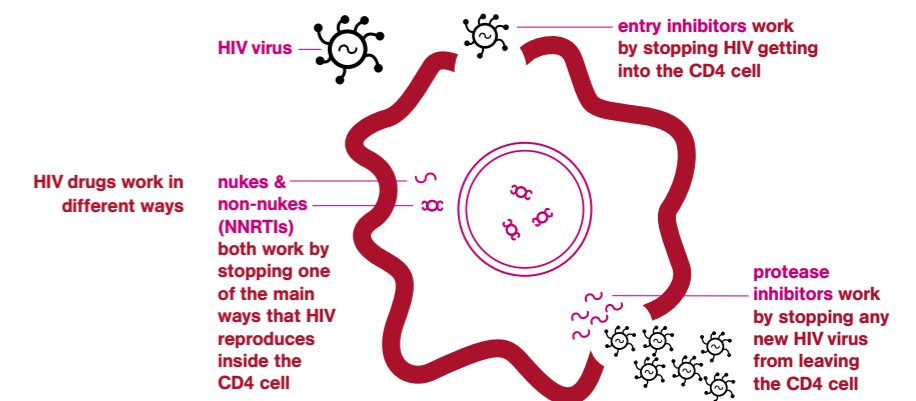
'mL' is an abbreviation for millilitre or cubic millimetre, a standard measurement for volumes of liquid – another abbreviation for this is mm³

Even if you are well, it is a good idea to get to know something about treatment now, before you need it. This is particularly important if your CD4 count is falling, or if you have a high viral load.

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 anti-HIV drugs.

Although you may be worried about using treatments, HIV and AIDS is still a very real and life-threatening illness. It is possible to delay treatment until it is too late. Illnesses that can occur at any time when your CD4 count is below 200 can be fatal.



Adherence

Why it is so important

What is adherence?

Adherence is a word to describe taking your drugs exactly as prescribed. This includes taking them at the right time. It also includes following any special diet restrictions.

It is important that you develop a routine. Treatment for HIV involves a complicated daily schedule. You may need some support to get used to the changes it makes in your life. Adherence can be very difficult.

This is the most important thing you have to think about when you start taking a new combination.

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.

Many treatment centres now have an adherence clinic or an adherence nurse.

How much is enough?

Taking medication exactly on time is very important.

However, there is usually a window period of about an hour that is still okay. Some drugs, and some people, have a wider window period than others.

Because of this variation, it is still better to aim for the same time each day.

Diet restrictions are very important. Ignoring these can be like only taking half a dose. You will not absorb enough of the drug for it to work properly. Resistance is then more likely to occur.

This may mean you lose the chance to use these drugs in the future.

The next question is: 'exactly how close to perfect adherence do you have to get?'

Unfortunately, the answer is 'almost 100%'

Many studies have shown that even missing one or two doses a week can have a big impact on the chances of a successful treatment.

Even with 95% adherence, only 81% people achieved undetectable viral load levels. That is only one in every 20 doses that was missed or late.

Adherence rates

over 95%
90-95%
80-90%
70-80%
under 70%

% of people undetectable

81%
64%
50%
25%
6%

On the other hand, a US study of people in prison who took every dose showed much better results.

Because these patients were in prison, every dose was supervised. All had viral loads below 400 copies/mL after a year and 85% were below 50 copies/mL.

This result was more impressive than nearly every clinical trial. Most of these people had already failed previous treatments and so were even less likely to get a good result.

The point is not that you need to be in prison! It is that if you find a way to take all your drugs as prescribed, you will get good results.



Resistance

What is resistance?

Resistance to anti-HIV drugs occurs when the structure of the virus makes tiny changes. These changes are called mutations. This can mean that the drugs no longer work as well or even at all.

You can also be infected with a strain of HIV that is already resistant to some or all HIV drugs.

This is why UK guidelines now recommend that everyone should have a resistance test before starting treatment. You should have a resistance test if you have just been diagnosed with HIV, whether or not you plan to start treatment.

How does resistance occur? Mutations that lead to drug resistance are generally only produced when you continue taking a treatment with a detectable viral load.

If your viral load is still above 500 copies/ml after 2-3 months, or above 50 copies/mL after 6 months, you may need to change your treatment.

Your doctor should look closely at why the results are not as good as they could be. They will want to discuss how you are managing adherence and side effects. They should also test for resistance and possibly drug levels.

Resistance can develop even at low viral load levels between 50 and 500 copies/mL.

You should have a viral load test four weeks after starting or changing treatment. This should then be checked at least every 3 months when on treatment.

Get the results when they are ready (usually after two weeks). Don't just wait until your next visit.

It is better to get your blood tested 2-3 weeks before you see your doctor. Then you will have the results back for the appointment.

If your viral load has increased you should then get a second test on the same day, to confirm the results.

Often slight increases are due to errors in the test. You can also have small increases that go back down again that are called 'blips' or 'spikes'.

A re-test will check what is happening. If the combination is failing, you minimise the risk of further resistance by checking this straight away.

You will get a better response to a second treatment if you change when viral load levels are still low.

What is cross-resistance?

Some drugs are cross-resistant to others. This means that if you become resistant to one drug you will also be resistant to other similar drugs, even if you have never taken them before. This is particularly true of drugs in the same class.

There are also varying degrees of cross-resistance.

Sometimes you may still get some benefit from the second drug but the response is less likely to be as strong or as durable.

How do I avoid resistance?

Avoiding resistance is one of the most important conditions for using combination therapy. You need to use a combination that is potent enough to minimise the risk of getting resistance to any of the drugs 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.

If you are starting treatment, this is a realistic goal.

Letters and numbers: what they mean

Resistance mutations are usually given a number to say where on the virus that the change has taken place - like a junction on a motorway. If there is a letter afterwards, this stands for the new chemical that the mutation makes. If there is a letter before this stands for the chemical that should be there first.

Which drugs? Which combination?

The information on these pages is from the June 2006 edition of "Introduction to Combination Therapy". Information about HIV treatment can change. If you are reading this after June 2007, please check the i-Base website (www.i-Base.info) for updates.

Glossary of four main kinds of HIV drugs

RTI = nucleoside or nucleotide analogue, also called 'reverse transcriptase inhibitor' or 'nukes'

NNRTI = 'non-nucleoside reverse transcriptase inhibitor' or 'non-nukes'

PI = 'protease inhibitor'

EI = 'entry inhibitor' [T-20 (enfuvirtide) is the only EI approved and is not used in first-line therapy]

The strategy for using HIV drugs has been consistent for the last eight years. The main principle is that any combination needs to include at least three drugs.

Although this is still generally true, at the end of this section we also discuss a few different approaches.

Combinations usually include drugs from two different families. This involves choosing two 'nukes', plus either an NNRTI or a protease inhibitor (PI) boosted by ritonavir.

The best results have been using combinations like these. This is reflected in both UK and US treatment guidelines.

The UK treatment guidelines recommend the third drug to be an NNRTI, with a preference for efavirenz over nevirapine. This is mainly because NNRTIs require fewer pills or diet requirements than most PIs.

If you are not using an NNRTI as the third drug, UK guidelines now recommend that you should use a protease inhibitor boosted by ritonavir. This includes lopinavir/r (Kaletra), which has ritonavir inside the capsule.

It also includes saquinavir, fosamprenavir or indinavir, which all require a small dose of ritonavir to also be taken at the same time.

Atazanavir can also be used - although this is usually only after side effects with an earlier combination.

Atazanavir is a once-daily PI. The daily dose is 2x150mg pills when it is boosted by 100mg of ritonavir. If this dose causes side-effects, the ritonavir can sometimes be stopped and a slightly higher atazanavir dose (2x200mg) used instead. Ongoing studies may lead to atazanavir being more routinely used as a first-line choice in the future.

Protease inhibitors used for second-line PI therapy (tipranavir and darunavir) also need to be boosted by ritonavir, but both these drugs are designed for people with PI-resistance.

Using a small dose of ritonavir in these combinations provides better and more sustained drug levels. This reduces the risk of resistance. It also reduces the numbers of pills and dietary requirements compared to unboosted PIs. Some people though find even small doses of ritonavir increase nausea.

Whether you use NNRTI- or PI-based regimens will depend on discussions with your doctor, your previous health and whether you have any prior drug resistance.

AZT, used with 3TC in a twice-daily combination, has been widely used and studied. Until recently it was recommended as part of first-line therapy in both the UK and US.

The disadvantages of AZT are related to side effects of anaemia and fatigue. AZT can also cause lipoatrophy (fat loss). With short-term use, (up to a year) the fat loss may not be noticeable in most people, and may reverse when the AZT is then switched to tenofovir or abacavir.

However, UK guidelines do not now recommend AZT as first-line preference. They also recommend that people who are currently stable on AZT-based combinations should discuss whether they want to switch to an alternative nuke before fat loss occurs.

Tenofovir is a once-daily nuke that is cleared from your body by the kidneys.

Monitoring for kidney toxicity, and not using tenofovir with other drugs that are cleared the same way, are important safety cautions. Tenofovir is not linked to lipoatrophy.

Abacavir was originally approved as a twice-daily nuke, but more recently has been approved to be used once-daily. The main side-effect of abacavir is a hypersensitivity reaction that occurs in up to 7% of people who use this drug. Symptoms of the reaction include fever, rash, headache, sore throat, diarrhoea, abdominal pain, tiredness, nausea, vomiting, flu-like aches etc that get progressively worse each day. Anyone who gets these symptoms must seek urgent medical advice with a view to stopping the abacavir. Once stopped, abacavir must never be used by that person again, as the reaction can return with much greater severity and is potentially fatal.

In 2006, a new genetic test (HLA B-5701) started to be used more widely by clinics in the UK, to identify those patients at greatest risk of this side effect. A negative result with this test does not guarantee that you will not get this reaction, but it does greatly reduce the risk.

The concern of key resistance mutations with both tenofovir (K65N) and abacavir (L74V) is that these changes have cross-resistance to other nukes. For the small percentage of people who do not get a successful result, the resistance will be important.

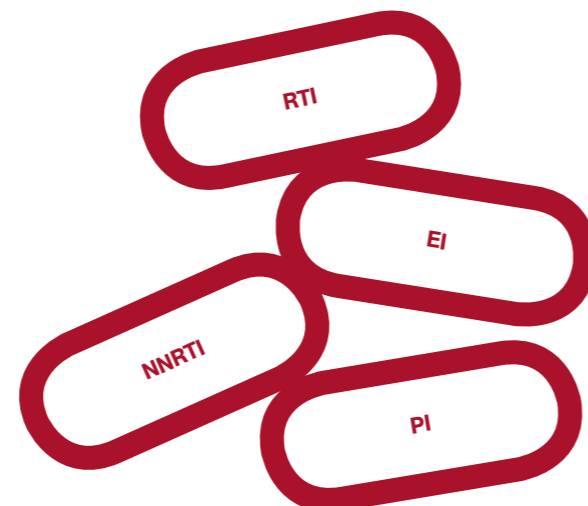
However, there is not clear recommendation to guide the choice between abacavir and tenofovir.

In relation to side effects, unless there is an interaction (see below), most nukes are interchangeable. This means that if you get side effects with one drug you can switch to another.

Nukes that shouldn't be used together

Some combinations of nukes should NOT be used together are:

- AZT and d4T
- 3TC and FTC
- ddl and tenofovir, especially with an NNRTI
- abacavir and tenofovir (in a 3-drug combo until an interaction is explained by further research).
- d4T and ddl should not be used together during pregnancy.



For more information

Participants

AIDS Foundation East-West (AFEW), Russia | www.afew.org

AIDS Infoshare
www.infoshare.ru

AIDS and Rights Alliance for Southern Africa
www.arasa.info

All-Ukrainian Network of PLWH, Ukraine
www.network.org.ua

Collaborative Fund
www.hivcollaborativefund.org

Community Health Media Trust/ Beat It | www.beatit.co.za

European AIDS Treatment Group (EATG) | www.eatg.org

Gay Men's Health Crisis (GMHC), USA | www.gmhc.org

Grupo de Trabajo Sobre Tratamientos del VIH (GTT)
www.gtt.vih.org

Ghana Treatment Access Group (GATAG) | www.gatag.org

HIV i-Base, UK
www.i-base.info

Legal Assistance Centre, AIDS Law Unit, Namibia | www.lac.org

Treatment Action Campaign (TAC) | www.tac.org.za

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Photography by Wolfgang Tillmans

The world's political and health leaders have committed to the goal of providing universal access to HIV treatment for all who need it by 2010.

But unless people with HIV receive good quality information about their disease and their medications, the full benefits of HIV treatment will not be realised.

Good treatment information helps people with HIV to make informed decisions, to understand the critical importance of adherence to HIV treatment regimens, to recognise the symptoms of advancing HIV disease, and how to manage treatment side effects more effectively when they occur. Informed patients and good treatment information can help healthcare workers provide appropriate care and maximise the benefits of their efforts and limited resources.

Treatment information also helps activists to understand the focus of their advocacy, to fight for their rights, to take a critically informed view of new scientific findings, and to drive and inform good treatment policies.

Many treatment activists have learnt the science and treatment of HIV. Many of us educate our communities on these issues using innovative ways developed in other communities. Activists and community members with HIV learn through songs, photos, booklets, pamphlets, games, posters, videos, workbooks, plays, fact sheets, and formal training. All these things help build what we call Treatment Literacy.

This report is from a global treatment literacy meeting in held in Cape Town – organised by the Treatment Action Campaign (TAC) from South Africa and HIV i-Base from the UK – to critically review existing treatment literacy materials, plan new collaborations to improve the quality of treatment literacy curricula, and explore new methodologies for sharing treatment information among diverse audiences and multiple cultures.

Community Health Media Trust (CHMT) in South Africa have produced treatment literacy DVDs with an animated sequence of the viral lifecycle. TAC show how they provide information to rural communities using songs and role-plays. Nava Kiran Plus (NKP) have translated and adapted i-Base materials, produced for the UK, for their community in Nepal. We hope that groups starting new treatment literacy programmes will use our experiences, borrow ideas, and be inspired.

We believe that good health outcomes can only succeed and thrive in places with strong support for community provision of health and treatment education. We believe community treatment literacy activists and educators will be critical to the success of ambitious plans to increase treatment access by 2010. We believe that universal access to HIV treatment can never become a reality without us.

