

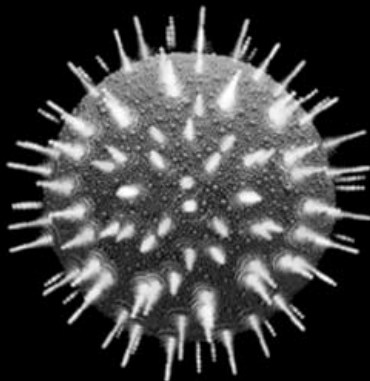


CARIBBEAN
REGIONAL
NETWORK +



*The Heart
of the Caribbean*

**TOWARDS A
POSITIVE FUTURE
UNDERSTANDING
ADHERENCE AND THE
EFFECT OR EFFECTS
OF TREATMENT**



BACKGROUND

The Caribbean Regional Network of People Living with HIV/AIDS (CRN+) is the only civil society organisation of regional scope, managed and working directly with the community of people living with HIV/AIDS (PLWHA) in the Caribbean. CRN+ takes pride in its vision as the authentic voice of PLWHA and to this end continues to work to ensure that the needs of PLWHA, based on priorities identified by PLWHA take precedence in all regional and national HIV/AIDS interventions. To meet these objectives CRN+ has developed this treatment and adherence booklet to assist PLWHA in managing their treatment.

INTRODUCTION

Change has always been a difficult process for human beings to become comfortable with if an extra effort and serious commitment are not adapted as main ingredients to its success.

HIV/AIDS has presented itself within our midst as one of the greatest challenges to face mankind, and as such, mankind must without fear be able to face HIV/AIDS.

One of the challenges for PLWHA is adherence to their medication. It should be noted that ARV treatment has been proven to greatly improve the standard and quality of life of PLWHA over the years. So, if a person is to extend his/her life, adherence to medication has to be paramount. When we consider that life-long plans were seen as a reality before the presence of HIV/AIDS, why then allow these plans to be changed by not adhering to the treatment of ARV? PLWHA must have the will to live on and lead a productive and enriching life to contribute meaningfully to society.

TOWARDS A POSITIVE FUTURE

UNDERSTANDING ADHERENCE AND THE EFFECT OR EFFECTS OF TREATMENT



What is HIV/AIDS?

- Human immunodeficiency virus (HIV) causes infections in humans. It passes from one person to another through semen, vaginal fluid, blood, or breast milk.
- The most common way to get infected with HIV is through unprotected sexual intercourse.
- HIV can also be transmitted (passed to another person) through injection needles or blades that have already been used on another person with HIV.
- Babies can get infected in the womb, during birth or through the breast milk if their mother has the virus. This does not happen every time, so the baby of an HIV positive mother might be HIV negative or HIV positive.
- There are two types of HIV, called HIV-1

and HIV-2. Most people have just one type but some have both.

- A person usually does not know that he or she is infected with HIV until a special blood test is done. If the HIV test shows that the virus is present, a person is said to be HIV-positive.
- At first, HIV infection does not make a person very ill. He or she may continue to have a healthy life for some months or many years.
- After some time, a person with HIV may start to lose a lot of weight, feel very tired and be unable to do all their usual daily activities. Illnesses also start to happen, especially infections such as tuberculosis (TB), herpes zoster (shingles) and other skin or chest infections. These are called opportunistic infections – the effect of HIV on the immune system provides opportunities for these infections to attack.
- AIDS stands for Acquired Immune Deficiency Syndrome. It is a physical illness that eventually occurs after HIV has done damage to the immune system.
- If people with AIDS do not get treatment, they will gradually become very ill and are likely to die.
- These diseases can also happen to people who are HIV-negative, but they are much more common and more dangerous when they happen to someone who has HIV.

What are HIV Testing & Counselling?

- To find out if a person is infected with the human immunodeficiency virus (HIV), it is essential to do an HIV antibody test. This uses a small amount of blood taken from the person who wants to know if he or she is HIV positive.
- If the first HIV test is positive, another test is usually done, to check that the first result was correct.
- Voluntary and confidential counselling for HIV testing (VCT) is an important method for ensuring that a person gets support before and after an HIV test, is given the right information, and is helped to deal with the consequences of the HIV test result. Wherever it is given, it should respect the person's need for privacy and confidentiality.
- Pre-test counselling can be given at a special VCT centre, but it can also be given in a health facility, over the telephone or in places where people who are at risk of being positive are likely to gather.

- Post-test counselling should be provided at the same time as the result of the test is given to the person. If the person is positive, they should be helped to deal with shock, fear or self-stigma and to work out how they are going to proceed. If the result is negative, the person needs support for avoiding HIV infection and related risks in future.

What is CD4?

Definition of CD4 -

CD4 cells are lymphocytes (T cells) with CD4 receptors that play a critical role in the function of the immune system to fight off infections.

Definition of CD4 Count -

CD4 cell counts are a measure of the patient's immune status. HIV attacks and destroys CD4 lymphocytes resulting in a lower CD4 count and thus lowering the body's immunity against infections. The reduced CD4 counts are associated with an increase in the number of episodes of opportunistic infections and continued disease progression, therefore, lower CD4 counts are associated with advanced HIV disease and higher CD4 counts indicate a reduced risk or opportunistic infections and improved health status. Measuring the number of CD4 cells in the body is one method of determining the function of the immune system. Normally CD4 counts range between 600-1200 cells. When the CD4 count falls below 200, the person is considered to have AIDS and therefore, has a greater risk of developing a host of opportunistic infections.



What is Viral Load?

The viral load indicates the amount of HIV in the blood.

Definition of Viral Load Count –

Like the CD4 count, the viral load count is a means of measuring the strength of a person's immune system. Whilst one hopes that the CD4 count in the body would be high, the reverse is true of the viral load count. If the viral load count is high, it means that the virus is in a period of greater activity, multiplying and producing more copies of itself, thereby further infecting and destroying new CD4 cells. Higher viral load counts are associated with a faster progression to AIDS and may increase the risk of transmitting HIV infection.



ADHERENCE & TREATMENT

What is Treatment?

In general terms, 'treatment' is the response to a particular physical ailment. In the case of HIV/AIDS, the first anti-retroviral therapy was used in 1996 to treat HIV infection. The goal of HIV/AIDS treatment is to achieve maximal and durable suppression of the viral load. This in turn reduces the destruction of CD4 Cells, decreases immune suppression and slows down disease progression.



What is Adherence?

- Adherence means taking doses of drugs and sticking to the treatment plan exactly as prescribed. It means taking the correct amount of drugs, at the correct time and in the correct way (for example, with the right type of food or fluid, and before or after a meal).
- Adherence is more than remembering to take pills. It is about:
 - making a decision to practice a healthy life style;
 - making treatment decisions that take time and commitment;
 - patient and health care providers having responsibility in the process of making and keeping appointments;
 - altering work and family schedules to ensure that follow up visits to your medical health provider are kept;
 - taking medication every time, on time, all the time for life.
- At least 95% adherence is needed for ARV treatment to work effectively. Missing even a few doses can cause treatment to fail, opportunistic infections or drug resistance to start.
- Adherence also involves storing drugs properly so that they remain effective and safe to use.

When should a person start treatment?

ARV Treatment usually starts only when HIV has damaged a person's immune system.

ANTI-RETROVIRAL (ARV) TREATMENT

What is ARV Treatment?

- Antiretroviral (ARV) treatment is treatment for HIV infection that includes using drugs that interfere with the way that HIV reproduces in the body.
- ARV treatment reduce a person's viral load. This means that ARV reduce the number of HIV present in a person's body.
- ARV treatment lower the ability of HIV to damage the immune system (the body's natural defence). It means that the immune system can recover its ability to defend a person from attack by other infections, enabling them to stay healthy and live longer.
- ARV treatment must be taken for life. If not, the virus will start to reproduce again and will cause AIDS.

Why is it important to know about ARV Treatment?

ARV Treatment brings new challenges for PLWHA and for their care givers. Treatment gives renewed health and a realistic possibility to resume family life, relationships, work and other activities, but the person using ARV Treatment also faces many practical, psychological and social challenges in achieving these goals.

How does ARV Treatment affect a person's ability to live with HIV/AIDS?

- ARV Treatment is a long-term (life-long) treatment for HIV infection.
- Without ARV Treatment, many people thought that being HIV positive was a death sentence. When people have ARV Treatment, they must adapt to living with HIV rather than dying from AIDS. They live with a chronic condition.

PLWHA preparation for ARV Treatment

- ARV is a complex treatment with multiple medications and once therapy is started, treatment is long-term. It is, therefore, extremely important for PLWHA to be properly assessed and prepared for this treatment.
- The initial medical assessment of the PLWHA forms the basis for the health care provider to set up a successful treatment adherence plan. PLWHA should expect that during the assessment, the health care provider should aim to learn as much as possible about his/her health and psychological background.

- The initial assessment should also include the following: the provision by the PLWHA of a detailed medical history to the health care provider so that he/she could learn about the PLWHA health including past illnesses, opportunistic infections, hospitalisations; mental health status – depression, dementia, substance abuse – alcohol, drugs, prior use of ARV' and other medication, the PLWHA's beliefs and attitudes about HIV and treatment, sources of social support, the PLWHA's current financial situation and to identify potential reasons why the PLWHA may not stick to the treatment regimen.

Why is it important for PLWHA to adhere to treatment?

- If ARV Treatment is used correctly, it can improve a person's health and quality of life and enable them to live for a long time.
- If adherence is very good, the amount of HIV in a person's body will reduce very quickly after a few weeks or months. This allows their immune system to start to recover, so that illness is reduced and health is regained.
- A very high level of adherence (at least 95%) is necessary for ARV Treatment to work effectively. Missing even a few doses of drugs can cause treatment to fail and opportunistic infections or drug resistance.

What can help PLWHA adhere to treatment?

- Involving the PLWHA in decisions about their treatment.
- Having a good relationship between the PLWHA and their health care provider.
- Regularly monitoring the progress of the treatment – through clinical check ups and asking specific questions about adherence.
- Involving a wide range of people – such as family, friends, other PLWHA and community leaders – in supporting PLWHA to adhere to their treatment.
- Providing opportunities for PLWHA to share their experiences with other PLWHA who are taking ARV Treatment successfully.
- Making the treatment regimen as simple as possible, for example, where possible, reducing the number of pills and linking doses to a person's daily routine.

Consequences of non-adherence

Drug Resistance – this happens when the HIV virus changes so that a particular drug cannot attack it. When this happens, ARV treatment can become ineffective; then a person's viral load increases and the immune system starts to develop complications again. Drug resistance happens much more easily if a few ARV doses are missed or taken at the wrong time.

How does stigma relate to ARV Treatment?

- Stigma and discrimination are two of the many challenges for people with HIV.
- Stigma prevents people from accessing HIV testing, care, support, treatment and prevention.
- Preventing and reducing stigma and discrimination are vital so that people are not discouraged from using or helping others with ARV Treatment.

How can stigma affect a person's ability to take ARV Treatment?

- When stigma stops PLWHA from accessing services for HIV testing, care, support, treatment and prevention, it also reduces their access to ARV.
- Stigma causes psychosocial problems, such as, anxiety, depression, guilt, shame and loss of hope. This can cause problems for PLWHA starting or adhering to ARV treatment.
- Taking ARV's may make someone afraid that they will be identified as having HIV.
- Secrecy and not being able to disclose their HIV status may make it difficult for PLWHA to keep ARV treatment medicines at home or to carry them around during work or recreation time.
- Stigma can isolate PLWHA from their family, friends and community. This means the loss of important sources of support for ARV Treatment.
- In some countries women, young girls and children are often more stigmatised than men. Women, young girls and children with HIV might therefore have greater difficulties in these countries in getting access or adhering to ARV Treatment. In other countries, men who have sex with men are stigmatised more and thus, adhere less to their treatment.
- Stigma can also extend to carers of PLWHA, including health workers. This can prevent them from offering support to people taking ARV, or from getting ARV Treatment if they need it themselves.

What can help to reduce the effects of stigma on ARV Treatment?

- Increasing people's knowledge about HIV and encouraging them to recognise that stigma and discrimination exist.
- Raising awareness of the benefits and availability of ARV Treatment.
- Including prevention in messages about ARV Treatment. This means showing people that prevention is still necessary for PLWHA taking treatment and that it is possible to avoid opportunistic infections such as TB, by taking medicines to prevent them.
- Involving PLWHA, especially those taking ARV successfully, in providing support and information. In this way, those who need ARV Treatment can see the positive results of treatment and experiences can be shared with the community of PLWHA and with health care providers who are responsible for referring people for ARV Treatment.
- Involving a wide range of people to provide a supportive environment for ARV Treatment, such as, health workers, families, communities, NGOs, community groups, traditional healers and faith-based organisations.

SIDE EFFECTS OF ARV TREATMENT

What are side effects?

- Side effects are the unintended actions or effects of a drug. The term usually refers to negative effects.
- Side effects are also sometimes called adverse drug reactions, adverse effects or toxicities.
- All medicines can cause side effects. They can vary from minor inconveniences to major problems.
- The side effects of many drugs are well known; however, when a drug is new and has only been used on small numbers of people, some effects may not have been seen as yet or are not fully understood.

What side effects may a person taking ARV Treatment experience?

- Different ARV drugs are known to cause a number of different side effects; however, not all side effects are experienced by everybody who takes ARV. Different people react to drugs in different ways.
- Some side effects – usually nausea, diarrhoea and tiredness – may appear soon after a person starts taking ARV; however, these do not last long, and they decrease in the following week. This is because the body gets used to the drugs, which allows treatment to continue without problems.
- Other side effects caused by some ARV drugs include skin rash, dry skin, chapped lips, discolouration of tongue, hands or feet, nail problems, insomnia and sexual problems. They also include central nervous system (CNS) problems, such as changes in mood, concentration or memory.
- Other long-term side effects can be serious. They may appear mild at first, but can indicate major problems. These include peripheral neuropathy (damage to the nerves that may manifest in pain e.g. hands, fingers), liver damage and lipodystrophy (this involves changes in fat metabolism, with fat gain or fat loss on various parts of the body).

(SEE **PAGE 12** FOR DETAILED INFORMATION ON THE SIDE EFFECTS OF ARV TREATMENT)

What happens if side effects cause serious problems?

- A person might decide he/she wants to stop taking the treatment or ask for different drugs.
- The PLWHA should consult with his/her health care provider before any final decision is made.
- The doctor might decide to change the treatment and use different ARV.

What support do PLWHA need to deal with side effects of ARV Treatment?

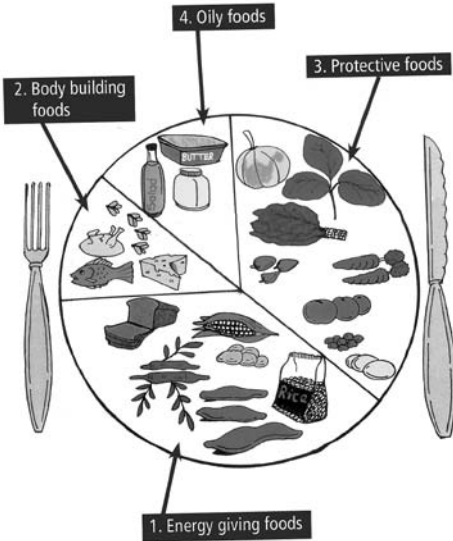
- PLWHA should discuss the possibility of side effects with their health care provider prior to starting treatment.
- If, after starting treatment a PLWHA has side effects, he/she should report any symptoms to his/her health care provider immediately. This is important because side effects can cause PLWHA on a treatment regime to stop taking ARV, or have low adherence. In addition, the health care provider may be able to identify what is causing the problems and what to do about them, such as changing the dose of ARV or changing to different drugs.

- PLWHA on a treatment regime should write down any side effects and symptoms they experience. This should include exactly what the effects are, how often they happen, how long they last and how bad they are.

How does ARV Treatment affect a person's eating?

- If a person is tired and lacks the energy to prepare meals, they might not eat enough of the right foods. If this happens, they should try to get support from their family, friends or home based care worker.
- Several ARV drugs cause side effects that affect a person's ability to eat. Some of these effects might disappear quickly, but others might last a long time.
- If any side effects continue for a long time, a person should see their doctor or health worker. This is because the effects might be due to another health problem or require a change in the ARV treatment.





REASONS FOR NON-ADHERENCE

- Forgetting to take medication
- People are too busy to take medication
- Medication finished and new prescription were not filled
- Patients were out of town
- Patients unable to attend clinic because of bad weather
- Falling asleep
- Patients are depressed
- Homelessness
- Patient too ill to take medication
- Afraid of domestic abuse
- Reluctant to take medication in front of other people for fear of discrimination
- Patient never fills their prescription
- Active substance abuse

How do ARV Drugs and food interact?

- Different ARV interact with food in different ways.
- Some ARV must be taken with meals which contain some fat, because this makes them more effective. Some others must be taken before meals so that they are absorbed quickly before food gets in the way. Others have to be taken after meals because they can irritate the stomach. For some drugs, it does not matter.

STRATEGIES FOR IMPROVING ADHERENCE

Strategies for improving Practical adherence

- Medication Diaries - These are diaries in which patients record the time and date of medication intake.
- Buddy System - The Buddy system relies on a friend, a family member or another PLWHA from a support group to help the patient to take medications regularly.
- Pill Chart - Pill charts are used to visually display the names of pills, their colours, shapes and sizes and the correct dosage (in terms of the number of pills that needs to be taken) for each medication.
- Personal Alarm - The cell phone alarm.

DETAILED INFORMATION ON THE SIDE EFFECTS OF ARV TREATMENT

• FOR BLOATING & WIND

What is it?

Due to difficulties in digestion, gas (wind) develops in the gut. This causes:

- bloating, which is swelling of the abdomen and/or stomach;
- sharp 'gripping' pains in the abdomen

Which ARV can cause it?

Bloating and wind: protease inhibitors, especially Indinavir or Nelfinavir.

Stomach pains: Zidovudine, protease inhibitors at the start of treatment.

What should a person do?

For bloating and wind:

Ask their doctor for advice.

- Drugs which alleviate bloating and gas can reduce absorption of other drugs in the intestine and reduce their effectiveness. So, they are not always recommended.

For stomach pains:

- Take antispasmodic drugs in early stages of ARV treatment, especially if using protease inhibitors.
- If strong pains suddenly occur during a treatment that is well tolerated, inform their doctor **immediately**.

How can a person prevent or reduce these effects?

For bloating and wind:

- Identify and avoid foods and drinks that make bloating worse (e.g. cabbage, onions, peppers, chillies, carbonated drinks, coffee, alcohol, very spicy food and, sometimes, milk).
- Eat while sitting down.
- Chew food well.
- If possible, take physical exercise, especially walking.

• DRY MOUTH OR CHANGE IN TASTE

What is it?

Producing saliva is important for making it easier to chew food and to protect teeth from decay. A bad taste in the mouth can discourage eating.

Which ARV can cause it?

Dry mouth: Several drugs, including ARVs, can cause a decrease in the production of saliva. This increases the risk of tooth decay

Change in taste: ARVs, especially protease inhibitors, can sometimes change a person's ability to taste and give the impression of having a bad taste in the mouth.

What should a person do?

For a dry mouth, consult the doctor – who might be able to prescribe a drug to increase secretion of saliva.

How can a person prevent or reduce these effects?

For a dry mouth:

- Chew chewing gum to stimulate the production of saliva.
- Drink water frequently.

For change in taste:

- Eat menthol sweets or chew gum to change the taste in the mouth.

• DIARRHOEA

What is it?

Some ARV can stimulate the gut to move too quickly, resulting in diarrhoea

Which ARV can cause it?

Didanosine (tablets in particular), Nelfinavir, Indinavir.

Diarrhoea is common at the start of ARV treatment, but it disappears after some weeks. It might continue when taking a drug such as Nelfinavir. Some opportunistic infections or HIV itself can also cause diarrhoea. If diarrhoea persists, consult a doctor.

What should a person do?

Treat diarrhoea quickly, because it can cause dehydration. It can also cause loss of weight and loss of important nutrients from the body.

- If the diarrhoea happens when starting ARV treatment, use anti-diarrhoea medicine to stop it, such as loperamide. Such medicines should not be used for more than 3 days without consulting a doctor.
- If the diarrhoea continues even when taking anti-diarrhoea medicine, it might be caused by an infection, so a doctor might prescribe antibiotics.
- If an ARV causes persistent diarrhoea which cannot be controlled, a doctor might decide to change the ARV treatment.

How can a person prevent or reduce these effects?

Drink 2-3 litres of liquids during the day. Have soups, and unchilled sugared carbonated drinks (sodas), because these will help to replace the minerals lost through diarrhoea. (Open soda some minutes before drinking to allow gas to escape,).

- Avoid large amounts of tea, coffee, alcohol and milk, which make food pass more quickly through the gut.
- Avoid fats and sugary foods.
- Eat helpful foods such as oats, yoghurt, bananas, rice, rice water, cooked carrots.

• NAUSEA AND VOMITING

What is it?

Nausea and vomiting are common signs of illness or disturbance in the body. They can be caused by food, anxiety, or some medicines.

Which ARV can cause it?

Zidovudine, Combivir, Didanosine (caplets in particular), Indinavir, Nelfinavir.

What should a person do?

Ask the doctor for advice.

- The doctor might prescribe anti-nausea medication such as metoclopramide. It is important not to take such drugs without advice and not to take more than prescribed.
- Do not take Prepulsid (an anti-nauseant) with protease inhibitors (Indinavir, Nelfinavir).

How can a person prevent or reduce these effects?

Drink several mouthfuls of cold carbonated drink or lemon water in the morning when waking and before meals.

- Drink mint tea, or boiling water containing a small piece of peeled ginger.
- Eat small but more frequent meals.
- Eat more cold than hot meals.



- Avoid spicy or fatty foods.
- Limit consumption of coffee, cigarettes and alcohol.
- Do not go to bed immediately after eating.
- Keep a few dry biscuits next to the bed and eat one or two before getting up in the morning.

NB. If vomiting occurs some hours after taking a dose, do not repeat that that dose again - just take the next dose at the correct time.

• PANCREATITIS

What is it?

An inflammation of the pancreas - which is important for digesting fats and proteins. It can cause a serious infection. Symptoms can include:

- Strong pains in the stomach or back which start suddenly.
- Diarrhoea.
- Nausea.
- Vomiting

Which ARV can cause it?

Didanosine

What should a person do?

Inform the doctor immediately.

- The doctor will usually take a blood test to measure amylase and lipase. These are enzymes that increase when the pancreas is infected. If there is risk of infection, antibiotics will be prescribed

How can a person prevent or reduce these effects?

When recovering from pancreatitis:

- Avoid fatty foods
- Avoid alcohol



• KIDNEY STONES

What is it?

Small stones formed from crystals, which develop inside the kidneys.

Symptoms can include:

- Intense pain in the base of the spine that irradiates towards the bladder.
- Blood in the urine.

Which ARV can cause it?

Indinavir is removed from the body through the kidneys - where it sometimes forms stones.

What should a person do?

Consult the doctor.

- The doctor might prescribe an antispasmodic drug such as Buscopan and a pain-killer, usually an anti-inflammatory.

How can a person prevent or reduce these effects?

Drink 2-3 litres of water or other liquids per day, starting with 3-4 glasses during the half-hour following each dose of Indinavir. This can be any liquid – except alcohol, coffee, tea and milk which can cause other problems.

- Avoid drinking more than the recommended amount, because this might cause loss of nutrients from the body through the urine.

• LOSS OF APPETITE

What is it?

A decreased or lack of desire for food despite basic caloric needs.

A person on ARVs should eat properly, to recover quickly and make treatment work well.

Which ARV can cause it?

Loss of appetite can be caused by several ARVs, especially when starting or changing treatment.

It can also happen if a person is depressed or has pains in the mouth which make it hard to eat.

What should a person do?

Check with the doctor to find out if the loss of appetite might be due to the drugs that the person is taking

- Talk to a counsellor if depressed
- Do not stop taking ARVs

How can a person prevent or reduce these effects?

Choose tasty food for a balanced diet.

- Avoid sweets and coffee.
- Eat smaller, more frequent, meals.

• **HEPATIC (LIVER) PROBLEMS**

What is it?

Inflammation and other disorders in the liver. Symptoms can include:

- Increase in transaminase enzymes in the blood.
- In severe cases, jaundice.

Which ARV can cause it?

Many drugs can affect the function of the liver. These include ARVs, especially Nevirapine and Efavirenz.

The function of the liver is also affected by some natural or traditional medicines, excessive alcohol and the hepatitis viruses (A, B, C, etc).

What should a person do?

Ensure that their doctor takes regular liver tests, usually at the start of treatment and at the same time as checking the CD4 count.

- The patient must always inform the doctor if they are taking any other medication, including traditional remedies, as these can also affect the liver.
- If the person has a hepatitis virus, regular blood tests must be done to monitor the liver.
- If the level of transaminase enzymes increases too much, the doctor may decide to halt a treatment and prescribe another.

How can a person prevent or reduce these effects? it?

Healthy eating and drinking is essential for having a healthy liver:

- Avoid too much alcohol, smoking or fatty foods
- Do not take other medications when taking ARVs unless the doctor has said it is alright

• **LACTIC ACIDOSIS**

What is it?

A serious disorder of the blood. Effects can include:

- Immense tiredness without any particular reason.
- Sudden loss of weight.
- Digestive problems: nausea, vomiting, loss of appetite.
- Muscular weakness or repeated cramps.
- Stomach pains.
- Breathlessness.

Which ARV can cause it?

Stavudine, Didanosine, Combivir, Zidovudine, Lamivudine.

It can occur several months or years after first taking ARV treatment.

What should a person do?

Consult the doctor as soon as possible, especially if treatment has been tolerated well so far.

- The doctor will order a blood test to measure the level of lactate in their blood. If it is abnormally high, it can mean lactic acidosis.
- If this is the case, the person must be admitted to hospital and ARV treatment must stop immediately. Treatment can be started with different drugs later, after the person recovers

How can a person prevent or reduce these effects?

This is an unexpected and rare side effect. There are no known methods of preventing or foreseeing it.



• MUSCLE PAINS AND WEAKNESS

What is it?

Cramps or weakness in leg muscles.

Which ARV can cause it?

Zidovudine (AZT) and Combivir which decrease the amount of fat in the blood and can damage muscle cells.

What should a person do?

Take magnesium – to limit the effects of cramps.

- If muscle weakness progresses rapidly or cramps happen very often, along with tiredness, breathlessness or stomach pains, consult the doctor urgently – as there is a risk of lactic acidosis.

How can a person prevent or reduce these effects?

Take regular, gentle exercise

- If cramps happen, massage the muscle to relax it.

• PERIPHERAL NEUROPATHY

What is it?

These are problems of the nervous system. Symptoms can include abnormal sensations or pain in the feet, tingling, sensations of burning or strange feelings in the legs or feet.

Which ARV can cause it?

Didanosine, Stavudine and, on rare occasions, Lamivudine.

Anti-tuberculosis drugs, the HIV virus itself, or dietary deficiencies, can cause neuropathies.

Neuropathies can appear several weeks, months or even years after first taking ARV treatment.

What should a person do?

Consult their doctor immediately,

- For moderate pain, the doctor might prescribe anti-inflammatory drugs such as ibuprofen or indometacin.
- For serious nerve pain, the doctor might prescribe an anti-depressant or anticonvulsant which can also control pain.
- Use complementary treatments, such as: B vitamins, magnesium, calcium; massage.

How can a person prevent or reduce these effects?

Soak the affected foot in very cold water.

- Ensure shoes are not too tight.
- Do not stand or walk for long periods - take regular rests.

• LIPODYSTROPHY OR LIPOATROPHY

What is it?

Lipodystrophy is excess fat, which can occur in different places on the body: chest (with women in particular), stomach and neck.

Lipoatrophy is loss of fat: This can affect the limbs, buttocks and face.

Which ARV can cause it?

Excess fat is mainly caused by protease inhibitors: Indinavir, Nelfinavir, etc.

Loss of fat: is mainly due to nucleosides (Combivir, Lamivudine, Zidovudine, Didanosine, Stavudine).

These problems can appear after several months or several years of treatment.

What should a person do?

Talk to the HIV doctor. Changing treatment can sometimes reverse the changes

How can a person prevent or reduce these effects?

Exercise when possible.

- Maintain a balanced diet and avoid becoming overweight.
- Avoid smoking and alcohol



• TIREDNESS

What is it?

This is a general feeling of lack of energy that can occur even after a long rest. The symptoms often include feeling 'drained' during the day. It can last several days or even longer.

Which ARV can cause it?

ARVs can cause tiredness, particularly at the start of treatment. It takes about one month for the body to get used to the drugs.

If tiredness occurs or increases during a treatment that is well tolerated, it is necessary to consult a doctor.

What should a person do?

Inform their doctor.

- In some cases, the doctor might prescribe vitamins A, B, C and E, as well as magnesium, calcium and selenium. These must never be taken in very large quantities or they will cause problems.

How can a person prevent or reduce these effects?

Rest, but do not sleep more than normally needed.

- Try to maintain a balanced diet, with enough vitamins (e.g. from fresh fruit and vegetables).
- Avoid coffee and tea in large quantities, as well as alcohol.
- Exercise when possible.

• SEXUAL PROBLEMS

What is it?

Loss of sexual desire. Failure to achieve or maintain an erection for men and difficulty in reaching orgasm for women.

Which ARV can cause it?

Many people on triple therapy have experienced such problems, although it is not known exactly why it happens.

There might also be other causes. These include: tiredness, stress, depression, alcohol, smoking and drug use.

What should a person do?

A man with impotence might choose to take Viagra.

How can a person prevent or reduce these effects?

Speak to a specialist in sexual issues, such as a psychologist or urologist.

- Eat well and get enough rest
- Reduce alcohol, tobacco or drug use

• SKIN, HAIR OR NAIL PROBLEMS

What is it?

Changes in the texture and colour of the skin, hair and finger or toe nails, which can appear some time after starting ARV treatment

Which ARV can cause it?

Indinavir can cause several problems such as:

- Dry skin.
- Chapped (sore) lips.
- Change in the texture of head and body hair.
- Loss of body hair.
- Inflammation around the nails (whitlow).
- In-growing nails. (whitlow).

What should a person do?

Inform the doctor. The changes might also be caused by the HIV virus itself, or other factors.

- If the problems are very significant and continue for a long time, the doctor might decide to stop prescribing Indinavir.

How can a person prevent or reduce these effects?

For dry skin and cracked or sore lips:

- Keep the skin hydrated and keep the lips lubricated.
- Use shea butter on the skin.

• SLEEPLESSNESS

What is it?

Difficulty falling asleep, or waking in the night and failing to go back to sleep

Which ARV can cause it?

Efavirenz, especially at the start of treatment.

Sleeplessness might also be due to a many other causes:

- stress or depression,
- stimulants such as caffeine, tobacco or alcohol,
- anxiety about living with HIV or starting or changing treatment,
- other problems not linked to HIV.

What should a person do?

Inform the doctor.

- The doctor might decide to prescribe sleeping tablets (to help with sleep) or tranquillisers (drugs to combat anxiety). The choice must take into account possible interactions with ARVs.

How can a person prevent or reduce these effects?

Do not sleep longer than needed.

- Go to bed and get up at set times, because an irregular life can make insomnia worse.
- Exercise every day, preferably soon after getting up from bed.
- Have smaller meals in the evening so that the stomach is not full when going to bed
- Reduce or cut out stimulants, such as tea, coffee, alcohol and cigarettes. For example, drink herbal tea in the evening.
- Try to sit and relax before going to bed.
- If possible, create an area of calm in the home.



• DARK BLOTCHES, PURPLISH MARKS, SPOTS, ALLERGIC RASHES ON SKIN

What is it?

Marks which appear on the skin after starting ARV treatment

Which ARV can cause it?

Red blotches, purplish marks and spots: Efavirenz, Nevirapine and Delavirdine. These generally appear about two weeks after the start of treatment.

Allergic reaction on the skin: Nevirapine. This usually appears two to three weeks after starting treatment.

What should a person do?

For red blotches, purplish marks and spots:

- Inform the doctor – this type of skin problem can be the result of many other cause as well as HIV or ARV drugs.

For allergic rashes on the skin:

- Inform the doctor.
- This usually disappears and ARV treatment does not need to be stopped.
- In some cases, the doctor might decide to stop Nevirapine and start a different ARV instead.
- For the first two weeks of using Nevirapine, it is vital to take just one 200 mg dose. Then, if there are no negative reactions, the doctor will increase the dose to two tablets per day.



How can a person prevent or reduce these effects?

For dark blotches, purplish marks and spots:

- It is not usually necessary to use any medication
- If the doctor thinks there is infection, an antibiotic might be prescribed.

For allergic reaction on the skin:

- Itching can be relieved by using calamine or some other calming lotion on the skin

ACKNOWLEDGEMENTS

In addition to the work compiled by CRN+, we wish to acknowledge the following sources used to assemble this document:

“Positive Living – Treatment Preparedness & Adherence”:
Community Action Resource (CARE) in collaboration
with the Canadian High Commission

“Antiretroviral (ARV) treatment Fact Sheets 1 – 13”:
International HIV/AIDS Alliance

“Positive Living Handbook”
Central Board of Health, Lusaka, Zambia

CARIBBEAN
REGIONAL
NETWORK +



*The Heart
of the Caribbean*