PATIENT SELF MANAGEMENT AND CAREGIVER BOOKLET

HIV AND TB CARE, SYMPTOM MANAGEMENT AND END OF LIFE CARE

A guide for patients, family members and community caregivers
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The HIV/AIDS Pandemic is not only a grave socio-economic and cultural issue but also a developmental problem calling for new and concerted efforts and initiatives from both developed and developing countries. The care treatment and support for people living with HIV/AIDS (PLHA) has been undertaken in various ways by different countries. There have been different approaches in which individual countries have implemented the care and treatment programmes. WHO with its mandate as the UN technical agency on health issues was concerned in the disparity and the pace in which individual countries were addressing the scourge and the benefits accruing from their discrete and ad hoc initiatives with minimal achievement outcomes. The concerns were even more echoed by the current country initiatives and challenge of scaling up Anti-Retroviral drugs in the care and treatment of the PLHA.

Therefore WHO has developed the Integrated Management of Adolescent and Adult Illness (IMAI) approach to scale up a comprehensive HIV/AIDS care, treatment and prevention within the framework of existing health systems. This public health approach is based on the principles of standardization, decentralization and integration, and covers the whole range of HIV/AIDS-related treatment issues, ranging from clinical staging, to treatment of acute conditions and opportunistic infections, to anti-retroviral treatment and palliative care, with prevention integrated throughout. This approach supports a network model, with back-up for services provided at health centre and district hospital level by clinical mentors within a strengthened consultative/referral and back-referral system.

The approach was tested in Uganda with very encouraging results. This approach puts in place a comprehensive approach to HIV/AIDS care and treatment by making sure that the approach assumes a “bottom-up and not just a top-down” strategy. Peripheral Health facilities i.e. communities, dispensaries and Health Centres, take an active role in not only care and treatment, but also in the follow-up of the PLHA to avoid treatment defaulters and subsequently improve adherence to anti-retroviral therapy.

The IMAI toolkit is new and evolving. It includes patients educational tools (Patient Self Management and Care Giver Booklet; Patients Flipchart); Simplified Guidelines and Training Materials for Primary Care Facilities (Acute care, Chronic HIV and TB Basic Care with ARV therapy, Palliative care, General Principles of Good Chronic care, Wall charts and others).

The IMAI strategy also involves PLHA as patients who are experts in their own illness to support the training of health workers. This is a very effective training intervention, and also addresses effectively the need of increased number of trainers necessary for capacity building during rapid ART scale-up.

The guidelines and manuals after pre-testing in Uganda were adapted in many various countries like Mozambique, Ethiopia, Zambia, Swaziland, Kenya, Egypt etc, and now Tanzania. In Tanzania our adaptation process involved scrutinization of the whole approach to suit our geographical, political, cultural and technical contexts. The purpose was to ensure easy understanding of the IMAI guidelines. The focus was on editing in terms of content validity, language suitability and acceptability, cultural orientation of the text and pictures/illustrations
including synchronization of the materials to our national policies, protocols, procedures, drug list/formulary etc was thoroughly done and involving various Stakeholders or Actors in health.

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Tanzania is also better placed to finding the materials useful by our communities because of the use of one common language (Kiswahili), which will make the translation of the materials very easy and have wider audience applicability.

It is my sincere hope and conviction that this approach will definitely compliment our already started country-wide initiatives in scaling up the care and treatment plan and enable us reach our set targets that result into unbeatable achievements. Let us all aspire for more success and achievement in the war against HIV/AIDS using these guidelines. Thank you so much.

Mr. Wilson Mukama
Permanent Secretary
Ministry of Health and Social Welfare
Acknowledgements

These guidelines and basic materials for training on ART and comprehensive management of HIV/AIDS in Tanzania were adapted from the generic WHO Integrated Management of Adolescent and adult Illness (IMAI) materials. The adaptation process took a long time undergoing changes at different stages and involving quite a number of experts from different organizations and institutions from within and outside the country.

The Ministry of Health and Social Welfare would like to thank all the different experts who were involved in various ways to ensure that the generic IMAI materials become adaptable to the Tanzania context. We would first like to thank WHO for accessing to us the IMAI materials and funding for the adaptation process, which started by first orientation and training of the initial 6 Tanzanian experts on these materials in Masaka – Uganda in 2004. We appreciate the initial training because it resulted into the subsequent IMAI orientation workshops for adaptation purposes within the country, which was held at Kibaha (January 2005), and at White Sands Hotel - Dar es Salaam (October 2005). This exercise involved much more people, facilitated by a team of experts from WHO Headquarters in Geneva and coordinated by experts from WHO country office. The Ministry wishes to sincerely thank the IMAI team of facilitators from WHO – Geneva, led by Dr. Sandy Gove, which also included Dr. Asfour Fareed Ramzi and Ms. Marie-Helen Vannson. The WHO – Tanzania HIV team included the HIV Country Officer, Dr. Lamine Thiam, and coordinated by Dr. Stella Chale. In addition we thank the Social-Cultural adaptation team, coordinated by Ms Feddy Mwanga, and involving Dr. Thomas Scalway from UK, and Dr. Ezekiel Mangi from Muhimbili University College of Health Sciences (MUCHS).

We very much appreciate the valuable inputs provided by the different experts who participated in the two adaptation workshops in Kibaha and Dar es Salaam. The experts came from the following institutions, organizations, departments and programmes: Muhimbili University Colledge of Health Sciences (MUCHS) and Muhimbili National Hospitals (MNH); Bugando Medical Center (BMC); Mbeya Referal Hospital (MRH); Kilimanjaro Christian Medical Center (KCMC), and the Human Resource Development in the Ministry of Health and Social Welfare. Similarly the different programmes of the Ministry of Health and Social Welfare, – particularly; the National AIDS Control Programme (NACP), the National TB and Leprosy Control Programme (NTLP), and the Health Department of Dar es Salaam City Council.

The output of the two workshops in Kibaha and Dar es Salaam resulted into semi-refined IMAI materials suitable for the Tanzanian context and health delivery. The materials were further worked on (layout, editing, etc); by a team of experts before the pre-testing exercise. The team included a consultant for WHO Ms. Moher Downing, from University of California, San Francisco (UCSF) and others as local consultants, comprising of Drs. Bennett Fimbo from NACP; Robert Josiah of MNH, and Amos Odea Mwakilasas (MOH5W) as well as Mrs. Agnes Kinemo and Dr. Adeline Saguti (MOH5W). We thank for their tireless hard work that produced the final IMAI materials for in-country pre-testing and later printing. Similarly we thank the secretaries who were involved in typing the changes during the adaptation and compilation process. They include: Ms Gerwarda Mwatuka (WHO), Ms. Janeth Mbwani (WHO), Ms. Kijakazi Salum (NACP) and Ms Frieda Shauri (WHO).

We would also like to appreciate the contributions made by experts from Uganda Knowledge HUB, WHO/Geneva, Multidisciplinary IMAI National facilitators, Health Care Workers from Health Centres, and Expert patients (PLHA) from various regions of Tanzania who participated in the different stages of field testing and corrections of the adapted IMAI materials. Last but not least, the MOH5W highly appreciates great contributions from Mrs Leila Asfour (Geneva) and Macrographic Company (India) towards graphic designing of all the documents.

To all of you, and those not mentioned, the Ministry of Health and Social Welfare says thank you so much.
**Who should use this booklet?**

This booklet can be used by:
- People living with HIV, TB or other chronic diseases
- ART and ART/TB treatment supporters
- Caregivers who will help the patient during his or her illness
- Community health workers, in conjunction with the Patient Education Flipchart when educating and providing care to patients and caregivers.

If you are a **person living with HIV and TB**, the booklet will help you understand your disease better, to take care of your own health and to understand when you need to seek care from your health worker.

If you are an **ART or ART/TB treatment supporter, a caregiver for a person living with HIV or TB or a community health worker (CHW)**, this booklet will help you to provide good care and good advice.

If you are a **health care provider**, this booklet will be useful when talking to and educating patients, caregivers and treatment supporters about HIV/TB, prevention and on how to provide care at home.

This booklet is for people with HIV and TB, their family members, treatment supporters and community caregivers who give home-based care to patients with HIV and other long-term diseases.

- The booklet gives advice on:
  - Self-management: how to take care of their own health
  - Positive prevention: how to deal with prevention in the context of clinical care when HIV-positive
  - Prevention of TB transmission during illness.
  - Home-based care: in the household, how to take medicines (whether on ART or TB treatment), how to manage symptoms and when to seek care.
  - In addition, the booklet address special issues such as care for children, psychosocial support and end-of-life care.
How to use this booklet effectively

All people living with HIV/TB should ALWAYS first be assessed and treated by a health worker. The health worker or CHW can then train the person living with HIV, the ART/TB treatment supporter and the community caregiver.

If you are a person living with HIV or TB patient, an ART/TB treatment supporter or a caregiver:
A CHW or health worker should go through the booklet with you. Once at home, look at the illustrations and read the text. If you cannot read, ask your children, a friend or a neighbor to read it for you.

If something is unclear, ask your treatment supporter or caregiver to ask the CHW or health worker for further information. If you are experiencing something that you do not know or remember, look at the booklet to see if you can find the solution. In case of problems not explained in the booklet, seek help.

If you are a health worker or CHW: Use this booklet in your conversation with people living with HIV/TB patient ART and ART/TB treatment supporters and caregivers. Take them through the booklet comprehensively and refer to the section containing information and advice for the problems they are facing.

For any of the more serious problems, marked with a drum, you should seek help from a trained health care worker.
Blood and body fluid contact

Always use condoms unless you know your partner’s HIV status.

HIV is transmitted through close contact in 3 ways:

1. Unprotected sexual intercourse with an HIV infected person,

2. From an HIV-infected mother to her child during pregnancy, labour and delivery and through breastfeeding,

3. Direct contact with the blood or body fluids of an infected person.

4. Shared sharp objects

4. Unsafe blood transfusion
1. Unprotected sexual intercourse

- HIV and other sexually transmitted infections can be transmitted through unprotected sex with an infected person.

- However, even when you are HIV+, having protected sex is highly recommended if you and your partner agree.

- Even if on ARVs, a person living with HIV who has unprotected sex can transmit HIV; moreover due to prior exposure to HIV he/she may transmit resistant HIV and/or get re-infected. You should always use condoms even if you and your partner are both HIV+.

- Always use condoms consistently and correctly. (Look at next page.) This will prevent HIV and other STIs, as well as unwanted pregnancy.

- Discuss sex and condoms openly with your partner.

- Neither partner should be forced to do something he or she does not want to do. However, be firm about using condoms and do not compromise on this.

- Remember, not having sex is the safest way to protect yourself and your partner from HIV.
How you should use male condoms:

1. Use a new condom for each sex act. Check expiry date and open condom.

2. Place the condom on the tip of penis with roll and rim. Squeeze air from the tip of the condom.

3. Unroll rim of condom all the way down to the base of penis.

4. After ejaculation, hold condom and remove penis from vagina.

5. Knot condom to avoid spilling sperm. Throw used condom in pit latrine or burn it. Never use one condom with more than one partner.

Condoms should be put on at the beginning of intercourse, not just before ejaculation.
How you should use female condoms:

1. Check expiry date and open condom.

2. Make sure the condom is well-lubricated inside.
   Choose a comfortable position – squat, raise one leg, sit or lie down.

3. Squeeze the inner ring at the closed end.

4. Gently insert the inner ring into the vagina. Place the index finger inside condom, and push the inner ring up as far as it will go. Make sure the outer ring is outside the vagina and the condom is not twisted.
   **Be sure that the penis enters inside the condom and stays in it during intercourse.**

5. To remove, twist the outer ring and pull gently.
   Knot condom to avoid spilling sperm. Throw used condom in pit latrine or burn it. Never use one condom with more than one partner.
Practice safer sex to reduce the risk of HIV and other STI transmission and to avoid unwanted pregnancy.

- Stay faithful to one partner. One partner is safest. You should ALWAYS use a condom even if you are faithful.
- Remember: Having sex with a young girl or virgin neither cures nor provides protection against HIV.

If you are an adolescent:
- Delay sex until you are ready to deal with problems that can come from sex, such as HIV, other STIs and unwanted pregnancy.
- Explore sexual pleasure in other safe forms (masturbation, massage, touching, hugging).
- Stay faithful to one partner.
- Use condoms.
- Be strong in saying no to unsafe sex.

2. From an infected mother to her child

Mother to child transmission of HIV can occur:

- during pregnancy

- at the time of delivery

- after birth, through breast-feeding

Preventive measures need to be taken in order to prevent HIV+ mothers from infecting the child.
**From the mother to her child**

- If you or your partner is HIV positive, your unborn baby may get infected.
- Discuss the decision to have children or not with your partner.

> If it is difficult to talk to your partner alone, consider seeking help from a counsellor.

**If you decide not to have a baby:** ask a trained health worker about family planning.

**If you decide to have a baby or are pregnant already:**

There are drugs to take that can reduce the risk of passing HIV to your baby. Discuss this with a trained health worker.

- You need to take these drugs before delivery. During pregnancy, keep using condoms every time you have sex to protect against passing on HIV.

- An HIV-infected mother can transmit the virus to her baby through breast feeding. Discuss infant feeding options with a trained health worker.
For a care giver:

Check pregnancy status
- Check family planning status, ask date of last menstruation and assess pregnancy at each visit.

Family planning
- Refer to health worker for family planning counselling.
- Encourage condom use in all to protect from STIs, re-infection by HIV and to avoid transmission to sexual partners and undesired pregnancies (dual protection).
- Demonstrate condom use.
- Give condoms.
- If desired, a second method of contraception can be used at the same time for added protection against pregnancy (dual method).

If woman is considering pregnancy
- Discuss interventions available for PMTCT.
- Educate to resume condom use once pregnant, during breastfeeding and thereafter.
Chapter 1: How to prevent HIV and TB

Blood and body fluid contact
- Always use condoms unless you know your partner’s HIV status.

Pregnancy
Advise on:
- Risk of infection for the baby.
- ARV drugs can reduce the risk of passing HIV to the baby. The drugs need to be taken right before delivery and given to the baby within 72 hours post delivery.
- Continue to use condoms.
- Safer labour and delivery.

Breastfeeding
Advise on:
- Risk of infection for the baby through breast-feeding.
- Possibility of several options for infant feeding—advise to discuss what is best with a trained provider.
- Continue using condoms.
If you decide not to have a baby:

- If you are not yet on family planning, ask the health worker about it.

- If you are advised to use another form of contraception, such as a pill or an injection to avoid undesired pregnancy, it is still necessary for you and your partner to ALWAYS use condoms to prevent the spread of HIV and other STI.

- If you are on ARVs or TB treatment, remember to tell your health worker. Sometimes ARVs, TB drugs and contraception pills do not work well together. Even when on ARVs you should ALWAYS use condoms. ARVs do not protect from spreading the HIV virus.

If you decide to have a baby:

- There is a risk that the baby will get infected with HIV from the mother. If you are considering pregnancy, talk to your health worker about what you should do, even if you are already on ARVs.

- There are ARV drugs to take that can reduce the risk of passing HIV to your baby during pregnancy, delivery and breastfeeding. You need to take these drugs exactly how the health worker tells you.

- During pregnancy, continue to ALWAYS use condoms every time you have sex to protect against passing HIV to your partner or getting re-infected.

Talk to your health worker on how you can ensure safe labour and delivery.

Since an HIV-infected mother can transmit the virus to her baby through breast-feeding, discuss infant feeding options with the health worker.

There are several options, and you and your partner will need to decide what is best for you.
3. Blood and body fluid contact

The risk of getting infected with HIV through non-sexual body fluids is very low, but it is important for family members and other people who take care of a person living with HIV/AIDS to be careful to avoid infection.

In order for the patient to feel more comfortable with this, explain that it is aimed at protecting the sick person as well as yourself from further infections. Do not share any sharp objects that can come in contact with blood—such as toothbrushes, razors, needles or instruments for tattooing, circumcision or scarification.

4. Be careful with sharp objects.

- Clean up spills of blood or other body fluids, always wearing gloves or plastic bags to protect hands.

- Avoid direct contact with open wounds of the sick person. If contact occurs, wash immediately with soap and water.

- Clean spills with diluted bleach.

- Keep any open wounds or sores of the patient OR the caregiver covered with plastic (such as gloves and plastic bags) when you interact (washing, touching, etc.).

- Keep patient’s laundry separate from other laundry if blood, stool or other body fluids are on it. When washing the laundry, hold an unstained corner, rinse off the blood, stool or other body fluids with water and then wash with soapy water.
Always use condoms unless you know your partner’s HIV status.

Never Give Up

- Always wash your hands with soap and water before and after touching the sick person and after contact with body fluids.
- Dispose things used for cleaning (such as cotton wool or toilet paper) by burning or throwing in a pit latrine.
- Use diluted bleach to wash surfaces/tools that have come into contact with patient’s body fluids.
- Wear gloves or put plastic bags over your hands when handling body fluids or when dressing wounds.

**How to prevent TB transmission**

Patients can spread TB, but they can also prevent the spread of TB

TB spreads to others when someone with TB coughs or sneezes, spraying TB germs into the air. Others may breathe in these germs and become infected.

Patients can prevent the spread of TB by:

- Taking their treatment regularly
- Covering the mouth and nose when coughing or sneezing
- Opening windows and doors to allow fresh air to flow through the home.
Chapter 1: How to prevent HIV and TB

Blood and body fluid contact
Always use condoms unless you know your partner’s HIV status.

Never Give Up
HIV is a virus that attacks the defense of your body and makes it weak. When the body is weak, it is easier to get cough, diarrhoea, fever and other problems. But how does this really happen?

How your body fights illness

- Each of us has a shield that protects us from getting sick. We call this our immune system. It helps us to fight diseases.

- We can imagine that our big shield, or body defence, is made up of little shields which keep our shield together and strong. These little shields are known as CD4 cells.

- We keep our shield strong by taking care of our health.

- Our shield helps us to fight different kinds of illnesses.
How your body fights illness

- Of course, our shield cannot prevent all illnesses. Some sickness arrows can pass. This happens more easily when our body is weak or when we are fighting other illnesses. Then we get sick.

- HIV hurts the body by making tears or holes in the shield. After several years, HIV will leave the body without a shield.

- With our shield gone, other illnesses like TB, pneumonia and malaria can pass through more easily and with more strength. We call these opportunistic infections.

- We keep our shield strong by taking care of our health.

- At first, when HIV arrows begin to strike the shield, it holds together and can look normal on the outside.
How your body fights illness

- On the inside, we can imagine there is a fight between the smaller shields (CD4 cells) and the HIV arrows in our body.

- Even when HIV+, we start out feeling very strong and well.

- This is because we still have many shields and not as many HIV arrows in our body.

- Therefore, being HIV+ does not mean that you will feel sick or that all people with HIV look sick.

- Over time, this begins to change.

- More HIV arrows are produced which attack more of the shields.

- We may feel weaker and have more experiences of getting sicker with different illnesses.

- With full-blown AIDS, there may be many HIV arrows in our bodies and almost no shields to defend us.

- We may experience many more strong illnesses because there is no defence at all.
How your body fights illness

• Normally, the progression of HIV looks like this.

• As the number of shields in our body goes down, our health gets worse, until we are very sick.

What can we do?

• Remember: being HIV+ does not mean that you will always feel sick.

• There are things we can do to repair our shields and even produce more shields to protect ourselves against the HIV arrows.

• Maintaining your shields may mean taking extra care to keep yourself strong. You need to avoid infections, because this will help strengthen and repair your shield.

We call this “living positively.” To live positively:

• Live your life as normally as possible.
• Tell someone you trust about your condition.
• Participate actively in life with others.
• Get emotional and spiritual support in times of trouble.
• Go to the health worker periodically as she/he tells you.
Minimize the risk of infection that attack:

Use condoms every time you have sex. This protects you from getting more HIV infection and other sexually transmitted infections.

Wash your hands with soap and water carefully after using the toilet, and before eating or preparing food. This protects you from intestinal problems.

Wash fruits and vegetables with clean water, and cook food (especially meat) thoroughly to reduce your chance of getting ill.
Blood and body fluid contact

Always use condoms unless you know your partner’s HIV status.

Use safe drinking water: drink boiled water or tea when possible.

Apply local antiseptic to minor wounds.

Store water in a clean container which prevents contamination.
Eating well can keep your immunity stronger.

Eating well can help keep your shield stronger

- Different types of food do different things to strengthen your immunity. This is why you should eat a variety of foods.

- Remember: you don’t have to spend a lot of money to eat well.

Foods that make you stay healthy/strong

You need to eat some food from all these groups: legumes, animal and animal products

- Proteins help you build muscle
- Cereals and roots give you long lasting energy
- Fats and sugars in moderation, are nourishing. They give you energy and increase body weight.
- Fruit and vegetables provide essential vitamins and are important for digestion.
- It is also important to drink plenty of clean and boiled water.
**Chapter 3: How to live well with HIV and TB**

**Blood and body fluid contact**

Always use condoms unless you know your partner’s HIV status.

**Never Give Up**

**Introduction**

**Blood and body fluid contact**

Always use condoms unless you know your partner’s HIV status.

**Tips to help intake and digestion of food:**

Avoid alcohol, smoking or non-prescribed drugs.

Eat many small meals a day.

Squeeze fresh lemon juice over meat and nuts.

Eat fermented foods.

**Drink between meals, not with meals.**
Be as active as you can!

Physical activity can make you feel better about your health. It keeps muscles strong and can prevent weight loss by stimulating your appetite, reducing nausea, and improving your digestive system.

Getting fit will help you feel good about your body.
Chapter 3: How to live well with HIV and TB

**Live your life as normally as possible**

- Tell someone you trust about your condition.
- Participate actively in life with others.
- Get emotional and spiritual support in times of trouble. This will reduce your stress and keep your mind and body strong.
- Go to the health worker periodically as she/he tells you.
Prophylaxis

There are also medicines that can help you avoid infections. If you are not taking any, ask your health worker. This is called prophylaxis.

The most commonly used is prophylaxis with Cotrimoxazole (Septrin). Cotrimoxazole can prevent some types of pneumonia, diarrhoea and brain abscesses.

There are other prophylaxis medications that the health worker can prescribe such as fluconazole or isoniazide.

**Remember**: if your immunity is fighting one thing, it is harder for them to fight another. By going to the health facility as soon as you feel sick, you will keep your shields strong.

Finally, even if you are feeling ok, go to the clinic as planned by the health worker.

HIV and TB patients can lead a normal life.
Chapter 3: How to live well with HIV and TB

Blood and body fluid contact

Always use condoms unless you know your partner’s HIV status.
What is ART?

• If your immune system is very weak, your health worker may consider giving a treatment called ART (Antiretroviral therapy). ART is a combination of three medicines called Anti Retroviral drugs (ARVs).

• The full name for ART is Antiretroviral Therapy.

How ART makes your immune system stronger

• ART does not cure HIV. It slows down the HIV virus from multiplying so fewer viruses attack the immune system. When you are on ARVs, your immune system gets stronger and can keep out opportunistic infections.

• When on ARVs, you will get sick less often and feel better for longer periods of time. ARVs will make you strong and can allow you to live a normal life. You will be able to go back to your work, school, take care of your children and enjoy life!
REMEMBER:

- It is important to start ARVs at the right moment. If your immune system is still strong you might not need ARVs, but you will still need to protect yourself from opportunistic infections.

**Always remember to practice prevention!**

- Even if your immune system is weak, you might not be ready to start ARVs. Your health worker will tell you whether you are ready or not.

**Here are some of the advantages and challenges of taking ARV drugs:**

Advantages:
- You can live longer and have a better quality of life.
- You won’t get sick as often.
- You will have more time to fulfill your dreams and goals.
- If you have children, you will see them grow up and go through life.
- You will have an opportunity to share your life experience with others (through writing, talking and other means of communication).
- You will have the opportunity to continue earning a living because you are well.
- You have more time to do things that you enjoy.

Challenges:
- ARVs is a life-long treatment that must be taken every day at the same time and in the same way.
- In the beginning ART seems complicated.
- Sometimes you have to adjust what you eat and when you eat it according to the drugs you take.
- Some types of ARV drugs require that you take several pills each day.
- Some types of ARVs may be harmful if taken with other drugs or during pregnancy.
- ARV drugs can give side effects. Some of them will go away after few weeks, while others will need to be addressed by the health worker.
- If you do not take your ARVs regularly, the medicine will not work anymore. This means that you will have fewer options for ARVs in the future.
Beginning ARVs is a big decision

Now, your health worker has told you that you are able to start ART. Your health worker can help you learn about ART, but the decision to start it has to be made by you. You are the only one who can determine if you feel ready to do so.

Make sure that you perfectly understand what this means and how it will affect your life.

Here are some basic facts about ARVs that you, your caregiver and your ARVs treatment supporter should know before starting treatment.

Always keep these facts in mind when you are on ART.

• When taken properly, ARVs will stop HIV from growing and spreading in your body. This will help you to have a normal life.

• ART is not a cure for HIV!

• You have to take tablets twice every day, at the same time, for the rest of your life.

• You may have to avoid certain foods and eat and drink at certain times of the day.

When taking ARVs, it is important to disclose your status to at least one person.

• This person will help you remember to take the drugs. She/he will become your treatment supporter.

• If you miss tablets, the HIV virus will get strong again, and ARVs will not be able to slow it down any more. It will stop working and HIV will come back even stronger.
• ARVs tablets only work for 12 hours. You can imagine that ARVs workers work in two shifts, a day shift and a night shift. If you don’t take your medicine regularly, the tablets will become too weak to do their job, so you need to take your medicine every morning and evening as instructed by your health worker.

• Because ARVs will not cure you of HIV, you can still infect your sexual partner and get re-infected with HIV. Therefore, you must continue to use condoms during sexual intercourse.

• Also, you and your caregiver should continue to apply all prevention measures mentioned earlier in this booklet.
**REMEMBER**

When on ARVs, remember to continue to live healthy and be considerate about your health.

- Continue to follow all instructions on prevention and positive living—such as eating well, protecting yourself from infection, being physically active and looking for support and care from your health worker if you do not feel well.

- Do not wait until you feel sick to talk to your health worker. Visit the clinic periodically or as advised by the health worker. Do not skip appointments.

If the caregiver or patient has any questions about ART or you are unsure about beginning ART, you should talk to your health worker about your concerns.

**Taking ARVs**

- Start ARVs only when you are ready to make a life-long commitment.
- Stopping and starting, and missing tablets, stops the ARVs from working.
- Taking some of the tablets, but not the others, also stops ART from working.

It takes practice to remember to take ARV drugs. Especially in the beginning, it helps to have someone you can trust, a family member or friend, to help you remember to take your drugs. This person is called your ART treatment supporter.

**REMEMBER:**

Taking ARVs is a big decision that requires a treatment supporter and advice from a health worker.
REMEMBERING ARVs – twice a day, every day

In the beginning your treatment supporter will remind you to take the treatment and to find out with you the best way to remember. Here are some ideas:

- Try to leave the ARV drugs in a place where they can be seen. This way the patient will be reminded to take them. If the patient has to hide his/her ARVs, they are likely to be forgotten. However, be sure to keep ARVs away from children.
- The ARVs should be in a place where the patient goes at the same time every day. For example, morning doses could be left next to the toothbrush and evening doses on the dinner table. (Do not leave them in a place where children might take them).
- If possible, use a pill chart. You can draw this on a wall board or piece of paper each week. Each time you take your dose, tick off the corresponding block on the chart. This way one knows whether the dose has been taken.

<table>
<thead>
<tr>
<th>Day of the week</th>
<th>Morning dose or</th>
<th>Evening dose or</th>
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- If you have an alarm clock or cell phone, you can set reminders.
- If there is something that you do at the same time every day, make this a time when ARVs will be taken.
- Pillboxes are a tool that can be used to check that the pill dose is taken every day. The pillbox must be refilled every week.
You should always have enough medication. Make sure that you receive your new monthly supply of drugs before you run out. If you are left with extra pills at the end of the month, this might mean that you are missing some of your doses.

This is a problem which could lead to resistance. Have your treatment supporter assist you in adhering to ART, especially at the beginning.

If you plan to be away when a dose is scheduled:

- Take ARVs with you.
- Plan ahead for how you will take the ARVs when you are at work.
- If you go away for a few days, pack more tablets than you need in case you stay away longer than expected.
- Also, keep all medical papers safe for you to know which medicines to take at what time.
- Show health worker your records when you visit.
If you forget to take your tablets:
• If it is within four hours from the time you were supposed to take the tablet, take them. If it is later than four hours, take the next dose as scheduled, but do not double it.

If you are having problems taking your ARV drugs:
• Inform the health worker team if you have skipped doses.

If you want to stop taking ARVs:
• Before doing so, inform your clinical team.
• The clinical team can help you to address the problems ARVs might cause you.

Never share your ARV drugs.
• If you share the drugs, they won’t work for you or the other person.

Keep ARVs in a safe place.
• Like all medicines, keep ART in a safe place and away from children.

**ART side effects**
• Because ARVs are a strong drug against HIV, you might experience side effects.
• For a few people ARVs can cause more serious and stronger side effects
• These side effects can include rash, tingling in your feet, abdominal pain and vomiting.

• Whenever you visit the clinic tell the health worker right away about any side effects you’ve been having, even minor ones. This will help the health worker to make the medicines easier to take and to avoid more serious health problems.

• **Seek care urgently in case of**
Severe abdominal pain, yellowish coloration of eyes and mucous membrane, skin rash, becoming tired with difficult in breathing, bizarre thoughts or confusion.
ART, safe sex and pregnancy

- ARVs do not kill the HIV virus in the body. ARVs do not protect against re-infection of HIV.

- If you are taking ARVs, you can still infect and get infected with HIV again. There is more than one type of HIV. Getting infected by different types can make your immune system weaker.

- While you are taking ARVs, continue to protect yourself and others by regularly using a condom when you have sex.

- Although ART decreases the risk of passing HIV to the child, you can still get pregnant while you are on ARVs, and you can still pass HIV to your child.

- If you are pregnant or want to have a baby, it is very important to tell the health worker before starting ARVs. The health worker can help you to make a decision about what to do.

- Some ARV drugs are safer than others during pregnancy. Talk to your health worker about which ARV drugs to use.
Important information about TB:

- Tuberculosis (abbreviated as TB) is a disease spread by tiny germ that can float in the air.
- The TB germ may spray into the air if the person with TB germ in their body coughs, sneezes or even talks. Anyone nearby can then breathe TB germ into their lungs.
- People with TB have many different symptoms. The major symptom of TB in the lungs is coughing for more than 3 weeks.
- Other symptoms include discolored or bloody sputum, night sweats and pain when breathing or coughing.
- TB can be cured if the patient takes anti-TB drugs regularly, on schedule, for the full duration of their treatment.
- It is important for the TB patient to finish their treatment, or the disease may become resistant to treatment and become incurable.

A patient can prevent the spread of TB by:

- Taking regular treatment to become cured of TB.
- Covering the mouth and nose when coughing or sneezing.
- Opening windows and doors to allow fresh air to flow through the home.
- Avoiding crowded, closed spaces.
Pulmonary tuberculosis is one of the most common opportunistic infections that an HIV positive patient is exposed to.

Patients on TB-Art co-treatment will have a higher pill burden and therefore most likely will experience more side effects. It can be difficult to cope with the side effects and you might need special support for these two reasons.

Your health worker will provide information on how to cope and manage mild to moderate side effects. You should report to the health worker immediately for managing severe ones.

If it is not convenient for you to come to the health facility each day, your ART treatment supporter may be able to provide directly observed treatment (DOT) at your home.

Daily DOT is crucial during the initial phase of TB treatment and also during the continuation phase if you are taking rifampicin, in order to avoid drug resistance and also to control if you are not responding well to your drugs.

If you are also on ART, the daily DOT for TB should ideally be combined with the morning dose of ART.

If you miss a dose:
- Take the missed dose as soon as you remember, then continue according to the schedule.

- Do not take a double dose on any drug (The duration of treatment will be extended to complete all doses in the regimen).

As with ART, remember that if you are travelling you should think to take additional doses with you, to avoid running out of your supply.

Periodically, you will need to go the health facility for sputum collection for follow-up sputum smear examinations.
Possible TB drug side effects

✦ Possible minor side-effects are:
  - lack of appetite
  - nausea
  - abdominal pain (if this happens take drugs with food or gruel)

Note that orange/red urine should not make you worry as this is a normal side effect of the rifampicin drug.

Possible major side-effects for which you need to inform your health worker as soon as possible:
  - joint pain
  - burning sensation in the feet
  - itchy skin
  - skin rash
  - deafness
  - dizziness
  - jaundice
  - repeated vomiting
  - difficulty with vision
HIV is a lifelong disease. It is important for you to understand it, to feel comfortable about it and to manage the problems that it might give you.

It is very important that you are aware of the value of taking care of yourself. To a large extent, you are able to control and influence the path which your health takes.

Once you have begun ART, this will assist you to regain your health. With these medicines AIDS becomes like any other chronic condition, just like diabetes or asthma. However, ART alone will not make you healthy. You must also take care of your health in other ways.

It might be difficult to be enthusiastic about your life when you have recently been diagnosed with HIV. Give yourself time to grieve. You might experience times when you feel angry, depressed, guilty or a range of other feelings. Allow yourself to feel these things. Eventually you might be able to let go of the negative feelings and accept your HIV-positive status.
Be involved in your care

Health workers and caregivers are there to help you care for you and to find solutions to the problems you are experiencing. However, the most important person for your health is yourself. As mentioned in Chapter 3, “How to live well with HIV”, every day you will need to make decisions about your health and others’ health:

• Sexual behavior and intimate relationships
  • If you feel safe enough, it is important to talk to your sexual partner(s) about your HIV status.
  • You need to prevent sexual partner(s) from being infected with HIV and other sexually transmitted infections.
  • You need to protect yourself and HIV+ sexual partner(s) from being re-infected with HIV.

FOR THIS, Use condoms during all your sexual encounters where there is a chance of body fluids (such as semen or vaginal fluids) entering another person’s body.
  • If you have decided not to have children at the moment, take the necessary action to prevent pregnancy. Remember that some contraceptives can be harmful if taken with ART. Check this with your health worker.

• Prevent and seek treatment for opportunistic infections

• Live positively and eat well

• Take your medicines as prescribed

• Avoid drugs or excessive alcohol
  • If you are on ARVs, or are sick with HIV on anti TB or both ARVs and TB drugs, drinking alcohol or using non-medicinal drugs can make you more ill.

ART does not go well with alcohol/drugs because:
  • They can make you feel more ill
  • It makes ART less effective

• It could cause you to forget to take your ART on time.
Avoid excessive alcohol, smoking or non-prescribed drugs:

- If you are on ART or are sick with HIV, drinking alcohol or using non-medicinal drugs can make you more ill.

ART does not go well with alcohol/drugs because:

- They can make you feel more ill
- It makes ART less effective
- It could cause you to forget to take your ART on time.
- An excessive amount of alcohol results in a loss of good judgement that may lead to irresponsible behavior.

You can control your use of alcohol/drugs by:

- Seeking professional help
- Reducing how much alcohol/drugs you use
- Avoiding alcohol/drugs completely
- Avoid smoking.
- Taking good care of yourself.

Avoid alcohol, smoking or non-prescribed drugs
When you go to visit the health care worker

Be in charge of your own health every time you visit the health worker! This will allow you to better understand your condition, the information given and the solution that the health worker will offer you.

• Learn more about your health and your treatment
• Use your visit to learn more about your condition, the medicines you are taking and how you can best address problems you are having at home. Also ask about the resources and support that are available for you. The more information you have, the better prepared you will be to take care of yourself

• If you need treatment, ask your health care worker what is available and how you can get it.
• Be sure to know the risks of treatment, and what will happen if you do not take it.

Ask Questions
• If you do not understand something, ask questions. If you do not understand the answer, ask again. You can also ask a family member, a friend, a caregiver or (if you are on ART) your treatment supporter to be with you to help you to remember what the health worker said.

Express Fears
• It is normal to have fears and it is okay to show them. Sharing with your health worker will make you feel better and also will help you understand better. Expressing your feelings will help you to be in control of your health.
Know the medicines you are taking

Make a List

- Get to know the medicines you are taking. You can make a list or just memorize their shape and color. If you have any doubts, ask your health care worker, treatment supporter, caregiver or family member.

- Take note of any problems you experience when taking certain medications. Be sure to tell your health worker about these problems. Take your medication with you, and ask your health worker or caregiver what you need to do in case the problems happen again.

Fluconazole? Perhaps I should go ask . . .
Understand the medicines you are taking

• Know about ARVs, TB drugs and other medicines you are taking

• Before you begin to take your medicines, be sure you know exactly HOW and WHEN to take them.

• All medicines need to be taken as prescribed. ARVs, in particular, will loose their effect if not taken every day, twice a day.

• TB drugs should be taken under direct observation (DOT) of a health care worker or treatment supporter

• You should also know how ARVs and other medicines might make you feel. ARVs and TB drugs might make you feel a little sick.

• Remember what the health care worker and the caregiver have told you. If you forget, look at your Patient Treatment Card whenever you have any doubts. It is important to know whether you can manage the problem on your own or whether you need to seek care from the health facility.

Knowing what Not to Take

• Some medicines do not mix well together and can make you very sick or lose their effect if taken together. If on ARVs, remember to always ask your health care worker what medicines you should NOT take when using the medicine you’ve been prescribed.

• Do not stop taking your ARVs, TB drugs or other medicines because you feel better on some days. Your ART medicine must be taken every day for the rest of your life, or until your health care worker tells you when to stop.
Get the results of every test

- Ask for Results

- Ask for the results of every test or procedure you have taken. By keeping your own record of test results, you will have more information about your health.

- Understand what the result means

- When you get your results, always remember to ask what the results mean for your health and for your treatment.
Sometimes your health worker may tell you to visit a different hospital to continue your treatment. In these cases, always ask:

- Why you are being referred.
  Knowing the reasons for referrals will help you to understand your problem better.

- How quickly you will need to go to the hospital.
  Knowing how quickly you need to go will allow you to plan ahead, so that you can tell your family and your caregiver.

- How much it will cost.
  Knowing the cost of your treatment will allow you to find resources for your visit.
Blood and body fluid contact

Always use condoms unless you know your partner’s HIV status.

Never Give Up

I would like to write here that I took a chest x-ray test and that I’m on TB drugs.

Explaining the Treatment

• Before you leave the hospital, ask the healthcare worker to explain what treatment you had and the new medicines you need to take, if any.
Always use condoms unless you know your partner’s HIV status.
Whether the patient is on ARVs only or on TB drugs, or on ARVs and TB co-management, it is important for you to use the following information as a treatment supporter.

If the patient is on ART, you must:

- Accept the patient’s HIV+ status
- Be committed to support the patient with ART for a long time
- Have gained the patient’s trust over time
- Be available to go to preparatory visits and to be educated on HIV and ART issues
- Be available twice daily, especially in the first months of ART
- Treat all information as confidential

You need to have gone through the following:

- Preparatory visits prior to starting ART
- Know what “being confidential” means
- Get educated on the Patient Education Flipchart, Patient Treatment Card and Patient and Caregiver Booklet
- Go through this booklet carefully
- Figure out how to remind the patient to take the medicine, to be present at the follow-up appointments, to help the patient keep track of all important test results and clinic history over time and to accompany the patient to support group meetings if possible.
- Know that you need to prevent your burn-out
- Be prepared to provide psychosocial support
If the patient is on TB treatment you must:

- Remind/encourage the patient to take their drugs everyday.
- Watch the patient take their drugs every day.
- Mark the treatment card after the drugs are taken
- Give her/his word for the drug intake to the health worker
- Collect drugs every week from the health facility
- Inform the health care worker of any problems encountered
- Accompany the patient to the health facility when needed
- Make sure the patient goes for the follow-up sputum exam.

If the patient is on ART-TB co-treatment you must:

- Give TB drugs and one dose of ART together
- Check whether patient has taken second dose of ART the following day.

What to do if the patient has difficulties in taking the drugs:

- Try to understand why the patient is not taking the drugs
- Discuss with the patient what he/she thinks the best solution could be
- Propose feasible solution and have the patient agree on the solutions you are proposing.
The symptoms discussed in this chapter might occur as part of having HIV/TB. It is important to know how to prevent them, how to manage them with local remedies and drugs or when to seek help from a health worker.
Chapter 7: Standard Precautions

Standard precautions
Health workers and caregivers are exposed to HIV and other blood borne illnesses such as hepatitis for example. As a caregiver of a person who is HIV positive, you are exposed to HIV and you should take some precautions called "standard precautions". The occupational risk of becoming HIV infected from caring for patients is very low (approximately 0.3%).

- Collect all used needles and sharps in puncture resistant container (box). Don’t fill the box completely to avoid accidental puncturing by needles or sharps objects which could be near the surface. When the box/container is three-quarter full, take it to the health centre where it will be disposed properly.

- Dispose things used for cleaning (such as cotton wool or toilet paper) either by burning or throwing in pit latrines for example. If the pit latrine is full, use another one.

- Use gloves when handling body fluids.

- Clean up spills of blood or other body fluids with diluted bleach.

- Make sure any wounds or sores on your own body are covered.

- Wash your hands as much as possible to protect you and to protect the sick person: before and after care, before and after going to toilet, before preparing food, before giving food or water to the sick person.
Accidental exposure to blood and body fluids

What to do in case of accidental exposure to blood or body fluids?

- Flush the site with large amount of running water.
- Wash with soap and water. If bleeding: allow the site to bleed a bit.
- Use of antiseptic is not recommended as it can have a caustic effect and is not recognized at being effective (however, in the absence of water, antiseptic can be used).

Seek help in case of an emergency from the health worker. He/she will know how to manage the exposure and will give you an appropriate treatment if needed.
Chapter 8: Preventing Symptoms

Body Hygiene

- Clean spills
- Separate stained laundry
- Cover wounds
- Wash your hands
- Throw away soiled items

- A tooth cleaning stick and a toothbrush
- Bed bath the sick person if he or she is unable to bath alone
- Caregiver cutting the nails of a patient

Always use condoms unless you know your partner’s HIV status.
Dry mouth

- Take frequent sips of drinks.
- Moisten mouth regularly with water.
- Suck on fruits such as pineapple, orange or passion fruit.
- Seek help from a trained health worker if dry mouth persists.
Treatment of hiccups

Hiccups can be unpleasant for the sick person. Treat hiccups by the following:

- Quickly drink cold water.
- Quickly take two teaspoons of sugar or honey.
- Rub with a clean cloth inside the top of the mouth. Feel towards the back of the mouth, where the top of the mouth becomes soft.
- Breathe into a paper bag/cloth, stopping when you feel uncomfortable.
- Hold your breath, stopping when you feel uncomfortable.
- Pull knees to the chest and lean forward (compress the chest).
Prevent bedsores in bedridden patients

Remember that always prevention is better than cure, therefore:

- If possible, help the bedridden patient sit up in a chair from time to time.
- Lift the sick person to change position in bed. Do not drag the sick person, as this breaks the skin.
- Encourage the sick person to move his or her body in bed whenever possible.
- Change the sick person's position on the bed often—if possible, every one or two hours, using pillows or cushions to hold the position.
- Keep beddings clean and dry.
- Look for damaged skin (change of color) on the back, shoulders and hips everyday.
- Put extra soft material, such as a soft cotton towel, under the sick person.

Change the position of the sick person in bed every 2 hours.

Points on the body where the patient is likely to get bedsores.
Preventing pain in muscles and joints

Due to long periods of inactivity and lack of exercise, the sick person may suffer stiff joints and muscle fatigue.

- Encourage the sick person to get out of bed if possible.
- Encourage the sick person to move in bed.
- Regularly massage the sick person with petroleum jelly or oil.
- Encourage exercise at least twice daily and help with movement of ankles, knees, hips, wrists, elbows, shoulders and neck.
- Hold the limb above and below the joint while moving it. Support as much of its weight as you can.
- Bend, straighten and move the joints as far as they normally go. Be gentle and move slowly without causing pain.
- Stretch the joints by holding as above but with firm steady pressure.

- **Exercise the wrists:** Bend wrists gently and slowly without causing pain. Apply pressure gradually. Repeat the exercise several times.

- **Exercise the elbows:** Gently lift the forearm up and down. Repeat the exercise several times.

- **Exercise the shoulders:** Gently lift the arm up and bring the hand above and behind the head. Move the arm from side to side. Repeat the exercise several times.

- **Exercise the knees:** Gently bring the knee up and to the side. Repeat the exercise several times.

In all cases, let the sick person do as much as he or she can do.
Preventing difficulty in passing stool (constipation)

In order to prevent constipation:
- Offer drinks often.
- Encourage fruits, vegetables or maize porridge.
- Encourage exercise if possible.

Prevent malaria

- Sleep under an insecticide-treated mosquito net.
- Close windows early in the evening.
- Use insecticide spray.
How to prevent other infections

- Use safe drinking water—drink boiled water or tea when possible. Store water in a container which prevents contamination. Use a spigot. Do not dip your hand or a used cup into the water.

- Eat well-cooked food. Wash fruits and vegetables well.

- Avoid people who have cold, flu, herpes zoster, or chicken pox.

- Practice good hand washing after using toilets, before preparing food, after sneezing or coughing, after touching genitals, after touching garbage or working in the fields.

- If possible, apply a local antiseptic to wounds after washing.
Managing Symptoms
Treatment of Bedsores

You can do the following to soothe the pain of bedsores and speed up the healing process:

- For small sores, clean gently with salty water and allow to dry.
- For bedsores that are not deep, leave the wound open to the air.
- For pain, give pain killers such as paracetamol or aspirin regularly.
- For deep or large sores, clean gently everyday with salt water, fill the bedsore area with pure honey or with ripe pawpaw flesh and cover with a clean light dressing to encourage healing.
- For bloody or smelling sores put on enough crushed Metronidazole (Flagyl) tablets to cover the area.

Seek help from a trained health worker for any discoloured skin or bedsores getting worse.
If the sick person feels like vomiting:

- Seek locally-available foods that the patient likes (taste may change with illness) and that cause less nausea.

- Offer or eat frequent small foods such as roasted potatoes, cassava or drinks such as water, juice or tea.

- Offer the drinks the sick person likes, such as water, juice or tea. Take drinks slowly and more frequently.

- There are some effective and safe local remedies for nausea, like licking ash from wood.

- If possible, avoid strong odours and cooking close to the patient.

Remember that vomiting and nausea can be side effects of medications, especially ART. Look at your patient treatment card.

Seek help from a trained health worker for vomiting lasting more than one day, dry tongue, passing little urine or abdominal pain or yellow eyes.
Feeding and managing weight loss

- Encourage the sick person to eat, but do not use force as the sick person may not be able to accept the food and may vomit.
- Offer frequent, smaller meals of foods the sick person likes.
- Let the sick person choose the foods he or she wants to eat from what is available.

If you are on ARVs and have difficulty eating, this could be a sign that ARVs is not working very well.

![Commonly available foods](image)

Seek help from trained health worker if you notice rapid weight loss or if the sick person consistently refuses to eat any food, or is not able to swallow.
Chapter 8: Management and Prevention of Symptoms

Blood and body fluid contact
Always use condoms unless you know your partner's HIV status.

If the sick person has mouth ulcers, seek the help of a health care worker. In addition, you can try the following:

• Avoid extremely hot or cold or spicy foods.

• Remove bits of food stuck in the mouth with a cotton wool, gauze or soft cloth soaked in salt water.

• Rinse the mouth with dilute salt water (a finger pinch of salt in a glass of water) after eating and at bedtime, or with a half teaspoonful of baking powder (Sodium bicarbonate) in a mug of water (500mls) if there are white patches in the mouth (thrush/candida).

• Use a soft tooth brush or stick to remove debris.

• If available, mix 2 tablets of aspirin in water and rinse the mouth up to four times a day.

Mix two aspirin tablets in a glass of water and rinse the mouth with the solution.

• Give soft foods, such as cold milk, porridge, potatoes or honey, depending on what the sick person feels is helpful.

• If possible, avoid strong odours and cooking close to the patient.

Seek help from a trained health worker if no response to home treatment, persistent sores, smelly mouth, white patches or difficulty swallowing. This could be a sign that your condition is worsening.
Diarrhoea

To help someone with this condition do the following:

- Give the sick person frequent drinks in small amounts: water, rice soup, other soups, rice porridge.
- Encourage the sick person to drink the above fluids as much as possible.
- Avoid very sweet drinks and alcohol.
- Mix Oral Rehydration Solution (ORS) and drink frequently.
- Encourage the sick person to continue eating.

Care for the rectal area:

- Put on gloves or polythene bags.
- After the sick person has passed stool, clean rectal area with toilet paper or soft tissue paper if available.
- Wash the rectal area when necessary, with soap and water.
- If the sick person feels pain when passing stool, apply petroleum jelly around the rectal area.

Remember: Diarrhoea could be the sign of a new opportunistic infection.

Seek help from a trained health worker for any of the following:

- vomiting with fever
- blood in the stool
- diarrhoea lasting for more than 5 days
- if patient becomes even weaker
- if there is broken skin around the rectal area. This could be a sign of a new opportunistic infection or a worsening of your condition.
For minor headaches:

- It could be a tension headache. Get a massage, rest and relax. It is common when fever is present.

- Take paracetamol (Panadol). Take 2 tablets every 4 hours, and aspirin or ibuprofen at night.

Remember: Headache could be a sign of a new opportunistic infection that needs to be treated by the health worker.

Seek care if headache does not go away and if you or your caregiver notice slurred speech, change in behavior and attention, pain in the neck, stiff neck, or some weakness in one side of the body.
Cough and difficulty breathing

For simple cough, local soothing remedies such as honey and lemon can help. Make a lemon tea sweetened with honey.

• Use local remedies, for example, steam with menthol or eucalyptus leaves.
• In addition to the treatment given by health worker:
• Help the sick person into the position that eases breathing. Usually sitting is best.
• Leaning slightly forward resting arms on a table may help.
• Use extra pillows for back support.
• Open windows to allow in fresh air.
  • If it is hot, you may fan with a newspaper or clean cloth.
  • Give patient water frequently (it loosens sputum).
  • Hit the sick person on the back and chest to loosen sputum and make it easier to cough.
  • Cover the mouth and nose with palm.

Safe handling and disposal of sputum:
• Handle sputum with care to avoid spreading infection.
• Use a tin with ash or sand in it for the sputum, then cover it.
• Empty the container in a pit latrine and wash the container with detergent such as JIK or OMO or clean with boiled water.

Remember: Cough or difficulty breathing could be the sign of a new opportunistic infection or an overall worsening of health.

Seek care if cough lasting more than 2 weeks, cough with fever and night sweats, cough with weight loss, fast breathing and if blood in sputum.
Skin problems

The following skin problems occur more often in PLWHA:

- rashes
- itchy skin
- painful sores on the skin (excoriations)
- increased dryness of the skin
- slow healing of the wounds
- boils and abscesses
- papules, vesicles (with shooting pain)

As a general rule, cleaning the skin frequently with mild soap and water and keeping it dry between washing will prevent the most common problems. Remember: Sometimes skin infections are a sign that the condition may be getting worse.

Very Dry Skin
Avoid soap and detergent, use bath oils and skin creams (Vaseline, glycerine, vegetable or plant oils can be just as effective as the more expensive oils and creams).

Rashes
Seek help from a trained health worker in case of:
- painful sores
- excoriations
- boils and abscesses
- vesicles (with or without shooting pain)

These could be a drug side effect or an allergic reaction especially if the patient is on ART.
Itchy skin is very common. It can be due to infections or the body’s reaction to the medication you are taking. This is a frequent side effect of morphine. It can be associated with a rash. You can help the sick person get some relief by trying any of the following:

To help the sick person get some relief:
• Cool the skin or fan it.
• Avoid heat and hot water on the skin.
• Avoid scratching, which causes more itching and sometimes infection.

Do not scratch.
• Tea leaves soaked in hot water are good against itching.
• Cut finger nails short and keep them clean to avoid infections.
• Use cool clothes soaked in water.
• Apply aqueous cream or Vaseline on the itching part of the body after a bath before drying.
• Put one tablespoonful of vegetable oil in 5 litres of water when washing the sick person.
• Rub the itchy skin with cucumber or wet tea bags (or tea leaves put in a clean piece of cloth and soaked in hot water).

Remember: Itchy skin could be a new opportunistic infection or a side effect of ARVs or anti TB drugs. Consult the Patient Treatment Card.

Seek care if itchy skin does not go away in a few days, if vesicles or peeling appear or if the problem extends to the eyes and mucosa.
Patients with confusion may show the following signs:

- forgetfulness
- lack of concentration
- trouble speaking or thinking
- frequently changing moods
- unacceptable behaviour such as going naked and using bad language

Remember: This could be a side effect of ARVs. As a caregiver, look at the patient treatment card.

- As far as possible, keep the patient in a familiar environment.
- Keep things in the same place—easy to reach and see.
- Keep a regular time pattern to the day’s activities.
- Remove dangerous objects.
- Speak in simple sentences, one person at a time.
- Keep other noises down (such as TV, radio).
- Make sure a familiar and trusted caregiver is present to look after the sick person.
- Take gradually more control of the medicines.
- Provide comfort for the sick person.
- Avoid confrontation (arguing).
- Do not say or do things that could upset the patient since he/she might still be able to understand.
- Use gentle reminders of place and time.

Seek help from a trained health worker if this is a new confusion or the sick person becomes violent, or for any condition not improving and causing distress.
Controlling pain

Pain is common and can be relieved.
All pain killers must be taken after meals or a snack.

- For mild pain in adults: Use paracetamol. Take 2 tablets every 4 hours, and aspirin or ibuprofen at night.

- For pain that re-occurs regularly after regular doses of paracetamol, add aspirin or ibuprofen in between doses of paracetamol and give aspirin or ibuprofen at night.

- In addition to giving medicines, talking to sick people and playing soft music can help them relax.

- Avoid things that make pain worse; for example, if dressing is stuck to a wound, soak it in clean water before removing.

- Move the sick person with care.

Seek help from a trained health worker for more severe pain. Pain control is possible.
Taking oral morphine

Oral morphine is a strong pain killer. If you have been prescribed oral morphine, follow these directions. Oral morphine should be taken:

- by the sick person
- by mouth
- by the clock (regularly by the sun/moon, or radio, approximately every 4 hours).

**The dose should be as prescribed.**

- Take doses regularly, every 4 hours during the day with a double dose at bedtime.

- Give an extra dose if pain comes back before next dose is due.
- Do not stop morphine suddenly.

Without the needle, draw the prescribed dose of morphine in a syringe. Drop the liquid from the syringe into the mouth. Pour the remaining morphine into the bottle.

**Side effects that may occur and their simple solutions**

- **Nausea**: It usually goes after a few days of starting oral morphine and does not usually come back.
- **Constipation**: It always occurs. Always give preventive local remedies such as dried papaya seeds or a laxative such as senna at night (see above).
- **Dry mouth may occur**: give sips of water (see above)
- **Drowsiness**: may occur in the first few days after starting oral morphine, but do not stop the morphine as the drowsiness usually goes away. If drowsiness lasts more than a few days, reduce the dose to half.
- **Morphine will help reduce diarrhoea. Never give a laxative if the patient has diarrhoea.**

Inform the health worker if:

- The pain is getting worse or you gave an extra dose.
- Drowsiness comes back or you had to reduce the dose.

**Do not stop morphine suddenly.**
Trouble sleeping

- Listen to the sick person’s fears, which may be keeping them awake.
- Reduce noise where possible.
- Give a comforting drink at night.
- Do not give the sick person strong tea or coffee late in the evening.
- Give treatment for pain if present.

Help with worries and fears

Take time to listen to the sick person.
- Discuss the problem in confidence.
- Providing soft music or massage may help the sick person to relax.
- Pray together if requested.

Seek help from a trained health worker if the sick person is abnormally sad, cannot sleep, shows loss of interest or threatens to kill themselves.
Chapter 9: End of life care
Providing emotional support near end of life

- Be aware that the sick person may go through a range of reactions from anger and fear to sadness and acceptance.

- Learn to listen, showing that you understand and feel what the sick person is going through.

- Be sensitive! The sick person may be thinking about losing family and friends soon, and may want to talk about this.

- Listen to the concerns of the sick person, counsel and give emotional support when needed.

- Encourage other family and community caregivers to do the same.

- Discuss worrying issues such as custody and support of children, school fees and funeral arrangement.

- Arrange for spiritual support if asked (respect the will and faith of the person, even when converted).

- Do not take the belongings of the sick person for your own benefit.
Preparation for death

Be compassionate, and be willing to talk about the concerns of the patient (see “Providing Emotional Support” above).

Provide physical contact, such as holding hands.

Provide care:

- Talk with the health worker about stopping some medicines.

- Keep giving pain killers. Make sure pain is controlled even if sick person is unconscious.

- Treat fever.

- Control symptoms to relieve suffering with diarrhoea medicine or antibiotics.

- Continue TB treatment to avoid spreading the disease to family members.

- Moisten lips, mouth and eyes.

- Keep the sick person clean and dry.

- Give skin care and turn the patient every 2 hours or more frequently.

- Eating little is OK when near death.

- Call a religious leader if the sick person asks.

If it is a child who is near the end of life:

- Be willing to talk and answer questions.

- Help the child feel loved and not alone.

- Ensure that family members are around to play when the child is able.
Chapter 9: End of life care

Blood and body fluid contact
Always use condoms unless you know your partner’s HIV status.

Never Give Up

Taking care of children whose parent is near the end of life

- Children need to talk about the loss of their parents. If you don’t talk to them, they may suffer more later.

- Allow time to talk about the disease and death with the children

- Talk in a simple and direct way so that they can understand.

- Help children feel that they will still be loved and cared for, even after their parent dies.

- Let them express their feelings and ask questions

- Do not take children away from their dying parent as they need to be close to each other.

Taking care of a child who is near the end of life:

- Be willing to talk to the child and answer questions.

- Help the child feel loved and not alone.

- Ensure that family members are around to play when the child is able.

- Involve the parents, brothers/sisters, or the other family members, or person that the child trusts to take care of the child and to talk to him/her.
Grieving after the loss of a loved one

Mourning and grief after the death of a loved one

Mourning is the natural process of accepting a major loss:
- It may last months or years.
- It may include religious events or just being with friends and family to share feelings about loss.
- It is very important that you express grief. Feeling sadness is a part of continuing to live.

Living with grief

It is natural to experience grief when a loved one dies. There are many ways to cope with grief.

You might want to:
- **Seek out caring people**: Find relatives and friends who can understand your feelings. Join support groups with others who have had similar losses.
- **Express your feelings**: Tell others how you are feeling.
- **Take care of your health**: You should try to stay healthy, eat properly and get plenty of rest. Be careful not to develop a dependence on medication or alcohol to deal with grief.
- Accept that life is for the living.
- **Hold off on major life changes**: Wait to make any major changes, such as moving, or remarrying, changing job or having another child, until you have time to adjust to your loss.
- Be patient: It can take months or years to grieve.
- **Seek help when necessary**: Getting help for grief is a sign of strength, not weakness.

Looking to the Future

With support, patience and effort, you will survive grief. The pain will lessen with time, leaving you with important memories of the person you have lost.
Burn-out is caregiver exhaustion. It can cause:

- Irritability, poor sleep, fatigue, poor concentration, emotional numbing, lack of joy, alcohol or drug use.

- The caregiver’s role can be a very demanding one. Caregivers might have times when they are tired, angry and disinterested in caring for the sick person. These are all normal reactions.

- At times the sick person might direct strong emotions (such as anger and blame) towards you. Often they do not mean to hurt you and are just generally frustrated with their own situation.

- Try to allow the sick person to express his/her feelings and frustrations freely. Try not to overreact to the person’s emotions. Try to find out if there is something they need and how you can help. The sick person might simply be afraid of being alone.

- If there are other family members that are willing and able to visit the sick person, this could be comforting for him/her.

- Caregivers who are close to the sick person sometimes feel guilty if they are well and their loved one is ill and dying. This is called ‘survivor guilt.’

- If possible, the caregiver should try to take regular breaks from caring for the sick person. Try to do something refreshing and relieving.

If you feel that you are facing burn-out, you should:

- Discuss this problem with other caregivers, family members and friends.
- Divide care tasks into manageable parts (small acts of care).
- Find somebody who can regularly replace you for periods of time.
- Do something outside the home, such as joining social gatherings, visiting friends or joining activity groups.
- Take care of your own health and take time to rest.
Now you are on ART that is:

<table>
<thead>
<tr>
<th>Table 1: Drug Combinations</th>
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<tr>
<td><strong>d4T-3TC-NVP</strong></td>
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</table>

**Week 1-2**
- Morning: d4T-3TC-NVP (combined tablet)
- Evening: d4T and 3TC (2 separate tablets)

**Week 3-on**
- Morning: Combined tablet
- Evening: Combined tablet

Remember that
- If you miss doses (even 3 doses in a month) **DRUG RESISTANCE** can develop. This is bad for you and your community. (These drugs will stop working).
- Drugs must be taken twice daily, **and miss no doses**. This is very important to maintain blood levels so ART can work.
- If you forget a dose, do not take a double dose.
- If you stop you will become ill within months or year.
- Drugs **MUST NOT** be shared with family and friends.
- If you find it difficult taking your pills twice daily, **DISCUSS** with health workers. **ASK** for support from your treatment supporter, family or friends.

It is common to have side effects. They usually go away in 2-3 weeks.

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If nausea or diarrhoea persist or get worse, or you have any of the following, report to the health worker **AT THE NEXT VISIT**.
- Tingling, numb or painful feet or legs or hands.
- Arms, legs, buttock, and cheeks become THIN.
- Breasts, belly, back of neck become FAT.

**SEEK CARE URGENTLY if:**
- Severe abdominal pain.
- Yellow eyes.
- Skin rash.
- Fatigue AND shortness of breath.
Now you are on ART that is:

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<td>lamivudine</td>
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<tr>
<td>nevirapine</td>
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If nausea or diarrhoea persist or get worse, report to the health worker **AT THE NEXT VISIT.**

**SEEK CARE URGENTLY if:**
- Yellow eyes.
- Skin rash.
- Pale or do not have enough blood.
- Fatigue AND shortness of breath.
Now that you are on ART that is:

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<tr>
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<tr>
<td>efavirenz</td>
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### Week 1-2
- Morning: d4T - 3TC (2 separate tablets)
- Evening: d4T - 3TC - EFV (3 separate tablets)

Remember that:
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- Tingling, numb or painful feet or legs or hands.
- Arms, legs, buttock, and cheeks become **THIN**.
- Breasts, belly, back of neck become **FAT**.

**SEEK CARE URGENTLY if:**
- Bizzare thoughts/confusion.
- Yellow eyes.
- Severe abdominal pain.
- Fatigue AND shortness of breath.
- Skin rash.
ART as soon as TB treatment is tolerated
(2 weeks, no anaemia, >50kg)

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- Breasts, belly, back of neck become **FAT.**

**SEEK CARE URGENTLY if:**
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- Yellow eyes.
- Skin rash.
- Fatigue AND shortness of breath.
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- Fatigue AND shortness of breath.
ART after intensive phase of TB treatment
(2 months, with anaemia, >50kg)

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**SEEK CARE URGENTLY if:**
- Severe abdominal pain.
- Yellow eyes.
- Skin rash.
- Fatigue **AND** shortness of breath.
ART does not cure HIV: SAFER SEX is still essential when on ART

Abstinence from sex is the safest method from getting or transmitting HIV.

If you wish to have a child, talk to the health worker before getting pregnant in order to decrease the possibility of passing on HIV.

Safer sex protects you from another HIV strain. If you get re-infected again with a different strain of HIV, your immune system gets weaker.

Continue to protect yourself and others. Use a condom each time you have sex. Always be mindful of your partner.

If you do not desire a child, talk to health workers about FAMILY PLANNING and use a second mode of contraception in addition to condoms (DUAL PROTECTION).

HIV CAN BE PASSED ON TO AN UNBORN CHILD IN ANY OF THE FOLLOWING STAGES

Pregnancy · · · · · · · · Delivery · · · · · · · · Breast-feeding

Some ART medicines are safer during pregnancy than others

USE PMTCT

Some ART medicines are safer to use while you are pregnant. Talk to your health worker about which ART medicines to use. Tell your health worker right away if you are pregnant or want to have a baby.