PATIENT SELF MANAGEMENT AND CAREGIVER BOOKLET

for common problems for Chronic HIV management and End of life care

A guide for caregivers

Draft
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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) or “uNompilo”,

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.

The booklet gives advice on:

- Self-management: how to take care of your own health if HIV+.
- Positive prevention: how to deal with prevention in the context of clinical care when HIV-positive.
- How to live with HIV.
- How to manage and prevent simple side effects and opportunistic infections
How to use this booklet effectively

All people living with HIV/TB should ALWAYS first be assessed and treated by a health worker.

The community health worker or CHW can then train the person living with HIV, the ART and/or 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 neighbour 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 warning, you should seek help from a trained health care worker.*
Each of us has a shield that protects us from getting sick. We call this our immune system or body defence. 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.

HIV is a virus that attacks the defence system or shield of your body and makes it weak. When the body is weak, it is easier to get cough, running stomach, fever and other problems.

But how does this really happen?

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 stronger. 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.
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 sick with different illnesses.
- With full-blown AIDS, there are many HIV arrows in our bodies and almost no shields to defend us.
- We may feel very ill and weak because there is no defence at all.
- Normally, the way HIV attacks our body looks like this.
- As the number of shields in our body becomes less, our body gets worse, until we are very sick and cannot help ourselves.
What can we do?

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

- There are things we can do in living positively to repair our shields and even produce more shields to protect ourselves against the HIV arrows.
- Looking after your shields means taking extra care to keep yourself strong. You need to avoid infections like flu, because this will help to strengthen and repair your shield.

We call this “living positively.”

To live positively:
- Learn to love yourself
- Live your life as normally as possible.
- Tell someone you trust about your condition.
- Participate actively in life by yourself and with others.
- Get emotional and spiritual support in times of trouble.
- Visit the health worker often and as s/he tells you.
- Go to someone you trust when feeling sad, lonely and poor in spirit.
Chapter 1: What is HIV
HIV is transmitted through close contact in 3 ways:

✔ Unsafe sex

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

✔ Direct contact with the blood or bodily fluids of an infected person

Unsafe sex

- HIV and other sexually transmitted infections can be transmitted through sexual contact (vaginal, oral, anal).
- Use condoms at all times 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 or ask a trusted person to assist in this discussion.
- 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. Ask your health care worker how you can negotiate this issue.
- Even if on ART, a person living with HIV who has unprotected sex can transmit HIV and/or get re-infected. You should always use condoms even if you and your partner are both HIV+
- You should always use condoms when you and your partner are HIV+.
How to use a male condom:

1. Use a new condom for each sex act. Check expiry date and packet in not torn or damaged.

2. Pinch the tip of the condom to remove air, then place on the tip of penis with roll and rim facing downwards.

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. Wrap the used condom up tightly and throw away properly.

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

1. Open package carefully. Make sure the condom is well lubricated inside.

2. 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 the 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.

5. To remove, twist the outer ring and pull gently. Throw away used condom properly.

BE SURE THAT THE PENIS STAYS INSIDE THE CONDOM DURING INTERCOURSE
Chapter 2: How to prevent HIV

Practice safer sex to reduce the risk of HIV and other STI transmission and to avoid unwanted pregnancy.

Stay faithful to one partner or reduce the number of your partners. 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.
From an infected mother to her child

Mother to Child transmission of HIV can occur:

- During Pregnancy
- At time of Labour and delivery
- After birth, through breastfeeding

Preventive measures like knowing your status need to be taken in order to prevent HIV+ mothers from infecting the child.
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 (prevention), such as a pill or an injection to avoid undesired pregnancy, it is still necessary for you and your partners to ALWAYS use condoms to prevent the spread of HIV and other STI.

- If you are on ART, remember to tell your health worker. Sometimes ART and contraception (prevention) pills do not work well together. Even when on ART ALWAYS use condoms. ART does 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 ART.

There are ART 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, **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 it is best for you.
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.

Be careful of sharp objects

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.

Always wear gloves or plastic bags on your hands for protection when you clean up spills of blood or other body fluids.

Use diluted bleach when cleaning up blood and body fluids

Clean Spills

Wash your hands properly and regularly
Keep any open wounds or sores covered with plastic (such as plastic bags) when you interact (washing, touching, etc.). This recommendation applies to you and the caregiver.

If you have open wounds, avoid direct contact with body fluids of the sick person. If contact occurs, wash immediately with soap and water.

**Cover Wounds**

Keep your 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.

**Separate stained laundry**

Dispose items used for cleaning (such as cotton wool or toilet paper) by throwing in a pit latrine.

**Throw away soiled items**
Chapter 3: How to live well with HIV

Minimize the number of HIV infection arrows that attack your shield.

Use condoms every time you have sex

Talk to your partner about using condoms to protect both of you.

Condoms protect you from getting more HIV arrows and other sexually transmitted infections.

Wash your hands carefully after using the toilet, and before eating or preparing food. This protects you from gastrointestinal stomach problems.

Keep small wounds and sores clean and get medicine from the local clinic to heal them.
Wash fruit and vegetables with clean water, and cook meat well to reduce your chance of getting germs that can make you ill.

Cover food to stop flies and insects making food bad.

Store water in a container which prevents soiling or getting germs (contamination).

Use clean and safe drinking water by boiling water or having tea.
Cleanliness

The teeth and mouth should be cleaned before and after meals.

Use a toothbrush or stick to gently clean and to remove food. **Do not share toothbrushes.**

Wash yourself daily with soap and water. If able, wash your own private parts, and then dry the skin gently with a soft towel. Oil the skin with cream, body oil, lanolin or vegetable oil.

Wash your clothes and bedding and dry them in the sun frequently. Use plastic sheets under the bed sheets to keep the bed dry when there is loss of control of urine or faeces. Air bedding out regularly in the sunshine.
Eating well helps keep your body stronger

Different types of food work differently in your body to strengthen your shield and can even produce more shields. This is why you should eat a variety of foods.

**Remember:** you don’t have to spend a lot of money to eat

Food that repair your shield and makes them stronger

**Remember:** if you are on ART and have difficulty eating, this could be a sign that ART is not working well.

Seek help from trained health care worker if:

- you notice rapid weight loss.
- you are not able to swallow.
Chapter 3: How to live well with HIV

Tips to help intake and digestion of food:

Avoid alcohol, smoking or non-prescribed drugs. Eat many small meals a day.

Eat fermented foods e.g. maas and Mahewu to help with digestion.

To avoid filling up with liquids do not drink with meals, only drink between meals.

Squeeze fresh lemon juice over meat and nuts to soften for digestion.
Be as active as you can!

Physical activity like walking, running, dancing can make you feel better about your health.

It keeps muscles strong and stimulates your appetite, reducing nausea, and improving your digestive system allowing food to be well used by your body.
Chapter 3: How to live well with HIV

Live your life as normal as possible

Tell someone you trust about your condition.

- Love yourself as you are
- Participate actively in life by yourself and with others.
- Get emotional and spiritual support when feeling sad or lonely. This will reduce your stress and keep your mind and body strong.
- Go to the health worker often and as s/he tells you.
Prophylaxis - medicines to prevent illness

There are also medicines that can help you avoid infections and becoming very ill. This is called prophylaxis.

The most commonly used prophylaxis medicine is with Cotrimoxazole (Bactrim). Cotrimoxazole can prevent some types of pneumonia, chest infection, diarrhoea (running stomach) and brain abscesses (sores on the brain).

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

Prophylaxis medications should be taken every day to prevent becoming very ill.
Finally remember: If your shields are fighting off one thing, it is harder for them to fight another. By going to the health centre as soon as you feel sick, can help keep your shields strong.

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

How to prevent other infections:

- Avoid contact with people who have a cough, cold, flu, herpes zoster (shingles) or chicken pox.

- Sleep under insecticide treated mosquito bed net, close windows early in the evening and use insecticide spray to avoid malaria.
Chapter 4: What is Anti-Retroviral Therapy (ART)?

What is ART?

If your immune system (your shield or defence) is very weak, your health worker may consider giving you treatment called ART (antiretroviral therapy).

ART is a combination of three medicines called **antiretroviral drugs**.

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 ART, your immune system gets stronger and can keep out opportunistic infections when on ART.
**Remember:** It is important to start ART at the right moment.

If your immune system is still strong you might not need ART, 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 ART. Your health worker will tell you whether you are ready.

Here are some of the ADVANTAGES of taking ART:

- You can live longer and have a better quality of life.
- You won’t get sick as often.
- You will have more time to fulfil 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.
Your health worker will tell you if you are ready to start ART

Here are some of the CHALLENGES of taking ART:

- ART 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 ART require that you take several pills each day.
- Some types of ART may be harmful if taken with other drugs or during pregnancy.
- ART 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 ART regularly, the medicine will not work anymore. This means that you and/or your community will have fewer options for ART in the future as limited drug regimens are available.
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 ART that you, your caregiver and your ART treatment supporter should know before starting treatment.

**Always keep these facts in mind when you are on ART.** (Also see *Patient Treatment Cards* in the Annexe page 65).

- **ART is not a cure for HIV!**
- When taken properly, ART will stop HIV from growing and spreading in your body. This will help you to have a better life.
- 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 ART, 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. (See page 40, the *Role of the Treatment Supporter*)

- If you miss tablets, HIV will get strong again, and ART will not be able to slow it down any more. This is a big problem called **DRUG RESISTANCE**. Drug resistance means that ART will stop working and the HIV arrows will come back even stronger, and the HIV will be harder to treat.

A treatment supporter will help you remember to take the drugs.
ART tablets only work for 12 hours.

Because ART workers work in two shifts, a day shift and a night shift. If you don’t take your tablets regularly, the tablets will become too weak to do their job, so you need to take your pill every morning and evening as instructed by your health worker.

Because ART 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; your partner and your caregiver should continue to apply all prevention measures mentioned earlier in this booklet.
Taking ART

**Remember:** When on ART, remember to continue to live healthily 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 often or as advised by the health worker. Do not skip appointments.

**Taking ART**

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

It takes practice to remember to take ART 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. (See page 40, the *Role of the Treatment Supporter*.)

**Remember:** Taking ART is a big decision that requires a treatment supporter and advice from a health worker.
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 ART drugs in a place where they can be seen.
  - This way you will be reminded to take them.
  - If you have to hide your ART, they are likely to be forgotten.
  - Be sure to keep ART away from children.

- The ART should be in a place where you go 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 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 ART will be taken.
  - Pillboxes are a tool that can be used to check
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 will help you to know whether the dose has been taken or not.

Pill reminder chart

<table>
<thead>
<tr>
<th>Day of the week</th>
<th>Morning dose</th>
<th>Evening dose</th>
</tr>
</thead>
<tbody>
<tr>
<td>MONDAY</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>TUESDAY</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>WEDNESDAY</td>
<td></td>
<td></td>
</tr>
<tr>
<td>THURSDAY</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FRIDAY</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SATURDAY</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SUNDAY</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Plan ahead!

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 when the drugs will stop working. 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 ART with you.
- Plan ahead for how you will take the ART 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 so you will know which medicines to take at what time.
- Show health worker your records when you visit.
Chapter 4: What is Anti-Retroviral Therapy (ART)

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 ART drugs:

- Inform the health worker team if you have skipped doses.

If you want to stop taking ART:

- Before doing so, inform your clinical team.
- The clinical team can help you to address the problems ART might cause you.

- Never share your ART drugs.
- If you share the drugs, they won’t work for you or the other person.
- Keep ART in a safe place.
- Like all medicines, keep ART in a safe place and away from children.
ARV drugs side effects

- Because ART is a strong drug against HIV, you might experience side effects.
- For a few people ART can cause more serious and stronger side effects.
- These side effects can include:
  - nausea and vomiting
  - funny taste in the mouth
  - diarrhoea (running stomach)
  - skin rash
  - excessive tiredness and muscle pain
  - headache
  - dizziness
  - sleep disturbance or nightmares
  - Tingling feeling in fingers and toes.

Check the Patient Treatment Card given to you by your health worker to see whether you have to go to the clinic or whether you can manage it on your own. (Also see Patient Treatment Cards in the Annexe page 58).

See Chapter 6, Preventing and managing symptoms, for the management of minor side effects.

At your next visit, inform the health worker of any new signs or symptoms.

Go to clinic or health worker immediately in case of:
Severe abdominal (stomach) pain, jaundice (yellow eyes, skin), skin rash, fatigue (tiredness), shortness of breath, pallor, bizarre thoughts or confusion.
ART, safe sex and pregnancy

- ART does not kill the HIV virus in the body. ART does not protect against re-infection of HIV.

If you are taking ART, 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 ART, 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 ART, 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 ART. The health worker can help you to make a decision about what to do.

Some ART medicines are safer than others during pregnancy. Talk to your health worker about whether you are on the correct medications.
Role of the treatment supporter

A treatment supporter is someone the patient trusts and has chosen to help them take their treatment.

This person could be a parent, a partner, son/daughter, friend, someone from a support group, a neighbour, teacher, caregiver, etc...

Whether the patient is on ART only or on ART and TB co-management, it is important for you to use the following information as a treatment supporter.

As a treatment supporter, 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.
- Read 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 ART-TB co-treatment:

- Be informed about TB and its treatment (symptoms, how TB spreads, how to protect others, etc...).
- Be sure that the patient is taking their daily TB (and HIV) medication.

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

- Allow patient to explain the problems in taking ART
- 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 solutions and have the patient agree on the solutions you are proposing.
- Participate in peer-support group meetings or meet the clinical team so that you can share the problems encountered and find possible solutions.
Tuberculosis and HIV/AIDS

Important information about TB:

- Tuberculosis (shortened to 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 the 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 2 weeks.
- Other symptoms include discoloured or bloody sputum, night sweats and pain when breathing or coughing.
- TB can be cured if the patient takes anti-TB drugs regularly, on time and 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 as the treatment will no longer work.

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 such as taxi’s, buses or waiting rooms.
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 (more pills to take every day) 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 the severe side effects.

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 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.

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

- Possible minor side-effects are: lack of appetite
- nausea (feeling of vomiting)
- abdominal (stomach) pain (if this happens take drugs with food or porridge)

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 (yellow skin or eyes)
- 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 guide yourself on the path which your health takes.

Once you have begun ART, this will assist you to regain your health. 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 take care of yourself 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 behaviour 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 partners from being infected with HIV and other sexually transmitted infections.
  - You need to protect yourself and HIV+ sexual partners from being re-infected with HIV.

To help you, use condoms during all your sexual encounters where there is a chance of bodily 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 (family planning or prevention methods) 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
- Tobacco, alcohol and harmful drugs prevents your body from healing

The most important person for your health is yourself.
Avoid alcohol, smoking or non-prescribed drugs

Excessive alcohol, smoking or non-prescribed drugs are harmful,

- 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 mix 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 behaviour.
- You will be at risk of being exposed to more infections

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 you.
- Choosing company that does not use alcohol/drugs.
- Not keeping alcohol/drugs in your home.
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.

- 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 them 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 colour. If you have any doubts, ask your health care worker, treatment supporter, caregiver, family member or support group.

- 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.
Understand the 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. ART, in particular, will lose its effect if not taken every day, twice a day.**

- You should also know how ART with other medicines might make you feel. ART 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* and ask your health worker 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 ART, remember to always ask your health worker what medicines you should NOT take when using the medicine you’ve been prescribed.

- Do not stop taking your ART 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 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.

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.

- **What do you need to take with you?**
  Knowing what documents, papers and medication to take, will help the health professional to assist you quickly.

- **Where will you be going?**
  This will help you to know how far from home you will be, cost of transport and taking meals with you.
At the hospital

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.
Universal precautions and Management

Health workers and caregivers are exposed to HIV and other blood borne illnesses such as hepatitis.

As a caregiver of a person who is HIV positive, you are exposed to HIV and you should always take some precautions called "universal precautions".

The 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 of properly.

- Dispose of 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 or plastic bags to handle 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 often 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 affected site with a large amount of running water.
- Wash with soap and water. If bleeding: allow the site to bleed a bit. Do not force the wound to bleed.
- Use of antiseptic is not recommended as it can have a caustic (burning) effect and is not recognized at being effective (however, if no water is available, antiseptic can be used).

Seek help from a health worker in case of an emergency. now how to manage the exposure and will give appropriate treatment if needed.
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
- Low healing of wounds
- Boils and abscesses, papules (small bumps), vesicles (blisters with shooting pain)

As a general rule, cleaning the skin frequently with mild soap and water and keeping it dry between washing will prevent most common skin problems.

**Remember:** Sometimes skin infections are a sign that the patient's 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).
- Use Aqueous cream as a substitute for soap.

**Rashes**

Seek help from a trained health worker in case of:

- Painful sores
- Excoriations
- Boils and abscesses
- Vesicles (blisters with or without shooting pain)

These could be due to a drug side effect or an allergic reaction especially if the patient is on ART.
Itchy Skin

Itchy skin can be due to infections or the body’s reaction to the medication the sick person is taking. This is a frequent side effect of morphine. It can be associated with a rash.

To help get some relief:

♦ Cool the skin or fan it.
♦ Avoid heat and hot water on the skin. Mix 1 tsp vegetable oil in 5L water to bath.
♦ Avoid scratching - it causes more itching and sometimes infection
♦ Apply lotion (Calamine) or diluted chlorhexidine 0.5% or ice blocks.

Do not scratch. Tea leaves soaked in hot water are good for itching, also cucumber.

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

Seek help if itchy skin does not go away in a few days, if vesicles or peeling appear or if the problem generalizes and extends to the eyes and mucosa.

Wounds

Uninfected wounds: wash with clean water. If possible apply an antiseptic. If possible, apply a local antiseptic to wounds after washing.

Remember: in PLWHA, wounds may take more time to heal.

Seek help if wound is infected (swollen, red, painful, with pus,...) and if fever is present.
Preventing pain in muscles and joints

The sick person may suffer stiff joints and muscle fatigue.

- Encourage the sick person to move in bed or get out of bed (if possible).
- Give warm baths and massage the sick person with petroleum jelly or oil.
- Encourage exercise 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 gently and slowly as far as they normally go.
- 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.
Prevent bedsores

- 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.
- Massage pressure points regularly, these are the points patients are likely to get bedsores.
- Encourage the sick person to move his or her body in bed whenever possible. Change position every two hours.
- Look for damaged skin (change of colour) on the back, shoulders and hips everyday
- Put extra soft material, such as a soft cotton towel, under the sick person, and prop the person up with pillows and cushions.
- Keep the bed clothes clean and remove all wet clothes and wet bed sheets.

In case of bedsores:
Report to a trained health worker and seek advice on treating the sores
How to care for bedsores

In the case of bedsores, report to the health worker for advice on care. For small and superficial sores, proceed as follows below.

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 bed sores that are not deep, leave open to the air.
- For pain, give pain killers such as paracetamol regularly.
- Keep changing position in order to avoid prolonged contact on sores.
- For deep or large sores - clean daily with salty water. Fill the bedsore with honey or paw-paw. Cover with light dressing

Seek help from a trained health worker:

- if sores are infected (red, swollen, pus or foul smelling)
- if the pain increases
- if passing little urine
- for appropriate drugs and dressing material
- If has fever

Applying honey or ripe pawpaw flesh to the bedsore may help

For foul smelling sores use activated charcoal or crushed Metronidazole
Chapter 7: Symptoms: prevention and management

Mouth ulcers and pain on swallowing

If you have mouth sores in your mouth or on your tongue it is recommended to:

- Avoid extremely hot or cold or spicy foods.
- Use a soft tooth brush or stick with cotton wool, gauze soaked in salty water to clean your teeth.
- Rinse the mouth with diluted salt water (a finger pinch of salt in a glass of water) after eating and at bedtime.
- If available, mix 2 tablets of aspirin in water and rinse the mouth up to four times a day.
- Eat soft foods, such as cold milk, porridge, boiled potatoes or honey, depending on what the sick person feels is helpful.

Remember: difficulty in swallowing and white patches can be a sign that the patient’s condition is getting worse.

Seek help from a trained health worker if:
- pain or difficulty in swallowing or persistent sores in the mouth.
- white patches that can be scraped off.
Nausea and vomiting

If the patient or sick person feels like vomiting:

- Take small frequent meals - eat slowly and chew well.
- Cool or cold meals are better tolerated than hot food.
- Give salty and sour foods. Avoid sugary foods.
- Advise to drink slowly and more frequently e.g. water, lemon juice or tea.
- Avoid the smell of cooking and foods with strong aromas e.g. cabbage, garlic and onion.

To reduce nausea:

- If due to ARV drugs, advise to take pills with food (except for DDI).
- Licking ash from wood is a safe and effective remedy for nausea.

*Remember:* Vomiting and nausea can be side effects of medications, including ART (common with AZT). Look at the Patient Treatment Card.

Seek help from a trained health worker if:

- nausea persists for more than 2 weeks
- dry tongue
- vomiting for more than 1 day
- passing little urine
- abdominal (stomach) pain or yellow eyes
Diarrhoea (running stomach)

To help:
- The person should drink frequently and in small amounts (water, rice soup, soups, porridges) and diluted unsweetened fruit juice.
- Drink as much as possible.
- If dairy products cause cramps use fermented products e.g. maas,
- Avoided Very sweet drinks, alcohol and coffee
- Mix sugar and salt solution (SSS) or Oral Rehydration Solution (ORS) and drink frequently.

Care for rectal area:
- Encourage patient to continue eating (small amounts frequently).
- After passing stool, clean rectal area with toilet paper or soft tissue paper every time.
- Wash the rectal area when necessary, with soap and water.
- If pain when passing stool, apply petroleum jelly around the rectal area. Mix salt with warm water in a basin. Sit twice daily if comfortable.

Remember: Diarrhoea could be the sign of a new opportunistic infection. Also it can be due to ARV. In this case, it usually improves in a few weeks.

Seek help from a trained health worker for any of the following:
- blood in the stool
- diarrhoea lasting for more than 5 days
- if you become even weaker
- if there is broken skin around the rectal area.
Cough and difficulty breathing

For simple cough, local remedies such as honey and lemon can help

- Make the sick person a lemon tea sweetened with honey.
- Use products such as Iboza drink or Vicks Vaporub.
- Help the sick person to adopt a position that eases breathing. Usually sitting is best.
- Use extra pillows for back support.
- Open windows to allow in fresh air.
- Encourage the patient to drink water sips of water often.
- Fan the patient and avoid smoke.
- Tap or slap the sick person’s back and chest to loosen sputum and make it easier to cough up.

If the cough is new or persists this could be TB. Consult with the health worker to send sputums.
Safe handling and disposal of sputum:

- Handle the sick person’s sputum with care to avoid spreading infection.
- Provide a tin with ash in it for spitting in, then cover it.
- Empty the container in a pit latrine and wash the container with detergent or clean with boiled water.

Remember: Cough or difficulty breathing could be a sign of a new opportunistic infection. If on ART it could be immune reconstitution syndrome (IRIS from rebuilding the defence system).

Seek care from a trained health worker for the symptoms below (if on ART seek care urgently):
- Fast breathing/chest pain
- Fever and night sweats
- Blood in sputum
- Symptoms lasting for more than two weeks
Fever

A fever (high body temperature) is not a disease in itself but a sign that something is wrong in the body and can indicated one of many different illnesses.

In PLWHA, fever often comes and goes.

**How to lower a fever**

- Remove any unnecessary clothing and blankets.
- Cool the skin by taking a bath in luke warm or cool water or pouring water over parts of the body. Put a wet towel or sheet on the patient.
- Provide plenty of drinking water to prevent dehydration due to the loss of liquid caused by the fever.
- Give paracetamol 500 mg tablets: 2 tablets every 4 hours but not more that 8 tablets per day
- Open the windows to allow cooler air in

Remember: if on ART, fever can be a sign of immune reconstitution syndrome (IRIS) or a new Opportunistic Infection (IO).

Seek help from a trained health worker if:

- suspicion of malaria (history of fever, no new rashes, no other apparent causes)
- fever persists for more than 7 days
- fever is accompanied by cough, weight loss, stiff neck, yellow eyes, diarrhoea, severe pain or confusion.
- the sick person is pregnant or recently had a baby
Headache

For minor headaches:

- It could be a tension headache that is common when fever is present.
- A massage of the scalp and neck can help.
- Help the sick person to rest and relax.
- Give paracetamol (Panado) 2 tablets (500 mg per tablet) every 4 hours, or ibuprofen (400 mg per tablet) at night.
- Paracetamol (500 mg tablets): do not give more than 8 tablets per day.

2 paracetamol (500 mg tablet) 2 paracetamol (500 mg tablet) 2 paracetamol (500 mg tablet) 2 paracetamol (500 mg tablet) 2 ibuprofen (400 mg tablet)

Early Morning Mid Morning Mid Afternoon Evening Night (with food)

Remember:

Headache could be a sign of a new opportunistic infection.

Seek care from a trained health worker if:

- headache persists more than 24 hours, despite taking pain killers or medication
- visual defects, vomiting present
- slurred speech
- pain in the neck and/or stiff neck
- weakness in one side of the body
- change in behaviour or attention
Managing pain

Pain is common and can be relieved.

Determine the **CAUSE of pain**:

- Where is the pain?
- What makes the pain better or worse? Describe the pain
- Is there a psychological or spiritual component?

Determine the **TYPE of pain**:

- Is it common pain such as bone or muscle pain or
- Is it common special pains such as shooting nerve pain, zoster (shingles), colic or muscle spasms?

---

**Grade the pain with FACES**
(epecially with children)

*or*

**with your HAND**
(0 is no pain, 1 finger is very mild pain and 5 fingers means the worst possible pain)

<table>
<thead>
<tr>
<th>FACES scale</th>
<th>HAND scale</th>
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<tbody>
<tr>
<td>![Smiley face]</td>
<td>![0: No hurt]</td>
</tr>
<tr>
<td>![Neutral face]</td>
<td>![1 finger: Hurts little bit]</td>
</tr>
<tr>
<td>![Sad face]</td>
<td>![2 fingers: Hurts little more]</td>
</tr>
<tr>
<td>![Angry face]</td>
<td>![3 fingers: Hurts even more]</td>
</tr>
<tr>
<td>![Crying face]</td>
<td>![4 fingers: Hurts whole lot]</td>
</tr>
<tr>
<td>![Sad face with tears]</td>
<td>![5 fingers: Hurts worst]</td>
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</tbody>
</table>
Additional methods for pain control

Additional methods for pain control can be combined with pain medications.

You can try:

- Emotional support.
- Physical methods (touch, stroking, massage, rocking, vibration, ice or heat, deep breathing).
- Cognitive methods (distractions such as a radio, music, or imagining a pleasant scene).
- Prayer (with respect to everyone’s practice and beliefs).
- Traditional remedies which are helpful and not harmful.

Pain killers:

- All pain killers must be taken after meals or a snack.
- For mild pain in adults: Use paracetamol (Panado) 500 mg tablets. Take 2 tablets every 4 hours, and ibuprofen at night (see p. 16).

Seek help from a trained health worker for more severe pain:

- pain control is possible
- stronger drugs like morphine can be prescribed
- if the sick person has been prescribed oral morphine, see p. 19
Oral morphine

Oral morphine is a strong pain killer. If oral morphine has been prescribed, follow these directions:

1. Pour the morphine into a small cup

2. Without the needle, draw some morphine into the syringe

3. Push the morphine into mouth.

1. Pour the remaining morphine into the bottle.

Oral morphine should be taken by mouth at regular times, approximately every 4 hours. Use a clock, the sun or the moon, a radio or another system to help you or the sick person remember.
Managing the side effects of oral morphine:

- Nausea usually goes away after a few days of starting oral morphine and does not usually come.

- Constipation always occurs. Always give preventive local remedies such as dried papaya seeds or a laxative such as senna at night. Increase fluid intake and bulk foods back.

- Morphine will help reduce diarrhoea. Never give a laxative if the sick person is taking oral morphine and has diarrhoea.

Inform your health worker if:

- the pain is getting worse
- the sick person took an extra dose of oral morphine
- drowsiness comes back
- you reduced the dose

If the pain is getting better, the dose may be decreased. Do not stop morphine suddenly.
Trouble sleeping

- Make sure the sick person is in a quiet environment so they can sleep well.
- Provide a comforting drink at night. Strong tea, coffee or other stimulating beverages should be avoided late in the evening.
- If pain is present, give a double dose of analgesic before going to sleep (but remember, do not give more than 8 paracetamol 500 mg tablets per day).

Remember: if on ART, this may be due to efavirenz.

Seek help from a trained health worker if:
- anxiety and nightmares are associated with pain
- if on ART and these symptoms last for more than 2 weeks from the start of ARVs.

Worries and fears

Encourage the sick person to talk to a trusted person (family member, friend, yourself). Encourage spiritual practices.

- A massage or soft music may help the sick person to relax.

Seek help from a trained health worker if the sick person is feeling abnormally sad, cannot sleep, or if he/she is experiencing a lack of interest or has suicidal thoughts.
The sick person who is confused

The sick person may be confused, showing 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 ART. As a caregiver, look at the patient treatment card and seek advice from a trained health worker.

- Make a bed for the patient on the floor. Assist with basic activities. If aggressive, the patient may require sedation. Provide emotional support for the family.

- As far as possible, keep the patient in a familiar environment, with objects always in the same place that are easy to reach and see. Keep a regular pattern in the day’s activities.

Seek help from a trained health worker if the confusion is increasing or the behaviour is getting worse.
End of life care

- 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.
- Try to allow the sick person to express his/her feelings and frustrations freely. Try not to over react to the person’s emotions. Try and find out if there is something special she/he needs and if you can help.
- 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.
- Discus worrying issues such as custody and support of children, school fees and funeral costs; try and arrange and prepare everything according to the sick person’s wishes.
- Arrange for spiritual support if asked (respect the will and faith of the person, even when converted).
Preparing for death

Be compassionate, and be willing to talk about the concerns of the patients concerns

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.
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.
- Let them express their feelings and ask questions.
- Help children feel that they will still be loved and cared for, even after their parent dies.
- Pay attention to the children’s behaviour and their feelings in the following weeks and months.
- Do not take children away from their dying parent as they need to be close to each other.

Taking care of a child 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 a person that the child trusts to take care of the child and to talk to him/her.
Mourning and grief after the death of a loved one is normal. Mourning is the natural process of accepting a major loss. It may last months or years. It is very important that you express grief. Feeling sadness is a part of continuing to live.

It is possible to live with grief and 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.
- Express your feelings.
- Take care of your health.
- Accept that life is for the living.
- Hold off on major life changes.
- Be patient.
- Seek help when necessary.

Try and look 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.
Caregiver burn out

Working as a caregiver is not easy and requires a lot of attention, time and energy. You should pay attention to yourself and take care of your own health, and adopting appropriate behaviour.

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 over react to the person’s emotions. Try to find out if there is something they need and how you can help.

The caregiver’s role can be very demanding, so caregivers may have times when they are tired, angry and disinterested in caring for the sick person. These are normal reactions and you should not feel guilty but you should try to find a way to manage them and avoid burn out.

The signs which can help you to recognize burn out:

- Irritability
- Fatigue
- Poor sleeping
- Poor concentration
- Avoiding the patient and other people
- Emotional numbness, lack of joy
- Alcohol or drug abuse
Be aware and pay attention to these signs for you and for the other caregivers and family member. Most of the time the individuals facing burn-out is unaware of it because they are so involved in their activities.

To prevent and respond to burn out:

- Define for yourself what is meaningful and valued in caregiving.
- Change approach to care giving: divide tasks into manageable parts (small acts of care); ask others to help; encourage self-care by the patient.
- Be aware of what causes stress and avoid it.
- Share your problems and feelings with other caregivers, family members and friends.
- Be aware that you can’t do everything yourself and that you can need help.
- Try to take regular breaks from caring for the sick person. Try to do something refreshing and relieving, and manage time for activities which are not related to care giving.
- Do something outside the patient home, such as joining social gatherings, visiting friends or joining activity groups.
- Take time to rest. Try to find somebody who can replace you for periods of time.
- Use relaxations techniques.
- Take care of your own health.
Now you are on ART

<table>
<thead>
<tr>
<th>TDF-3TC-NVP</th>
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<tr>
<td>tenofovir</td>
<td>lamivudine</td>
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<th>Week 1-2</th>
<th>Week 3-on</th>
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<tbody>
<tr>
<td>Morning: TDF-3TC-NVP (combined tablet)</td>
<td>Morning: Combined tablet</td>
</tr>
<tr>
<td>Evening: TDF and 3TC (2 separate tablets)</td>
<td>Evening: Combined tablet</td>
</tr>
</tbody>
</table>

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.

If you have:  

<table>
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<th>Do the following</th>
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<tr>
<td>Nausea</td>
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<tr>
<td>Diarrhoea</td>
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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 (tiredness) AND shortness of breath
Now you are on ART

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<tr>
<th>Week 1-2</th>
<th>Week 3-on</th>
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<tbody>
<tr>
<td>Morning: TDF-3TC-NVP (combined tablet)</td>
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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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<td>Muscle pain, tiredness</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 (tiredness) AND shortness of breath
Now you are on ART

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**SEEK CARE URGENTLY if:**
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- Bizzare thoughts and confusion
Now you are on ART

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**SEEK CARE URGENTLY if:**
- Yellow eyes
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- Bizzare thoughts and confusion
- Severe abdominal pain
ART does not cure HIV: SAFER SEX is still essential when on ART

No 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.

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.

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

- Pregnancy
- Delivery
- Breast-feeding

Safer sex protects you from another HIV strain. If you get reininfected again with a different strain of HIV, your immune System gets weaker.

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).

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

Annex: Patient treatment cards